

# Voices of Transformation:

## Developing Recovery-Based Statewide Consumer/Survivor Organizations

by the  
National Empowerment Center  
and the  
The Recovery Consortium



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# Voices of Transformation:

## Developing Recovery-Based Statewide Consumer Organizations



### INTRODUCTION

While professionals were still describing people diagnosed with “serious mental illness” as having a *lifelong condition*, for which the best possible outcome was maintenance, those of us with the lived experiences of severe emotional distress knew that we and others like us were able to achieve recovery. As mental health consumer/survivors, we understand the process of recovery because we are living it and bear witness to it. We understand that “everyone with a mental illness can recover”<sup>1</sup> and that all people can live full lives in the community because we are doing it every day.



This manual is a testament to the strength and dedication of all of us who have at one time or another been diagnosed with serious mental illness, and to our efforts to work in concert to help transform the mental health service system so that it better addresses the needs, desires, and realities of people living with – and without – serious mental illness.

The *Voices of Transformation: Developing Recovery-Based Statewide Consumer Organizations* manual has been developed by the National Empowerment Center (NEC) and the Recovery Consortium, which worked together to share their experiences in building viable and effective coalitions for transformation in their states, to identify the commonalities and differences in their experiences, and to provide guidance for consumer/survivor groups looking to develop or strengthen these initiatives in their own area and those wishing to support these initiatives. This manual provides an overview of the history of each organization, problems that were encountered by each, and the elements found to be essential in the creation of strong, sustainable, statewide, recovery-focused, consumer-run organizations. Our hope is that you will find the collective wisdom and experience described in this manual helpful as

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<sup>1</sup> President’s New Freedom Commission on Mental Health Report. (2003). *Achieving the Promise: Transforming Mental Health Care in America*. DHHS Pub. No. SMA-03-3832. Rockville, MD. Available: [www.mentalhealth.sambsa.gov](http://www.mentalhealth.sambsa.gov).

you seek to form new statewide consumer organizations and to strengthen existing ones.

As a consumer/survivor-run organization, NEC is one of five national consumer and consumer supporter technical assistance centers funded by the Center for Mental Health Services (CMHS) of the Substance Abuse and Mental Health Services Administration (SAMHSA) of the federal Department of Health and Human Services (DHHS).<sup>2</sup> The mission of NEC is to carry a message of recovery, empowerment, hope, and healing to people who have been labeled with mental illness.

The Recovery Consortium is a project of NEC designed to bring experienced consumer/survivor statewide networks together to exchange information and to collaborate on projects. The Recovery Consortium includes the California Network of Mental Health Clients, Ohio Advocates for Mental Health, On Our Own of Maryland, Inc., and Vermont Psychiatric Survivors.

## THE CONSUMER/SURVIVOR MOVEMENT

The idea that people can – and do – actually recover from serious mental illness grew in large part from the experiences and stories of the people who experienced recovery in their own lives. Their voices and perspectives were diverse and included people who were using mental health services or were “consumers” of services; “survivors” or individuals who believed they had survived despite their services and treatment by the system; and people who had once been patients receiving services and had moved beyond that status in their lives and were now “ex-patients.”

These voices and perspectives merged to form a movement that has not only survived, but has grown and emerged as a powerful force for change in mental health policy and psychiatric services in the United States and around the world.<sup>3</sup> The consumer/survivor/ex-patient movement has offered a different picture of “mental illness” than the one traditionally embraced by the mental health system, one that has begun to impact public policy and treatment practices.

*The consumer/survivor/ex-patient movement has offered a different picture of “mental illness” than the one traditionally embraced by the mental health system.*

As people with experience of living with a diagnosis of mental illness found each other and came together, they discovered a growing sense of personal empowerment in working collaboratively to improve conditions for themselves and others. Many found that joining with others and becoming actively involved in mental health advocacy,

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<sup>2</sup> Contact information for each of these organizations can be found in the Resources Appendix of this manual.

<sup>3</sup> Van Tosh, L., Ralph, R., Campbell, J. (2000). The Rise of Consumerism. *Psychiatric Rehabilitation Skills*. 4:3, 383-409.

social action, influencing policy, and developing peer support networks provided an important vehicle for personal as well as systemic transformation.

The consumer/survivor movement has three decades of experience in addressing and influencing mental health policy on all levels. Although there is still much that needs to shift, the work of the early consumer organizations made significant strides in paving the way for the current attention on system transformation and recovery-focused services and system transformation. These early organizations demonstrated the power of the collective voice and have a wealth of experience and wisdom to share.

## RECOVERY FOCUS: A NEW PARADIGM IN MENTAL HEALTH CARE

### *First, just what is recovery?*

*“Mental health recovery is a journey of healing and transformation enabling a person with a mental health problem to live a meaningful life in a community of his or her choice while striving to achieve his or her full potential”.<sup>4</sup>*

Recovery means different things to different people based on his or her personal background, culture, values and community. Recovery is about choosing to live a fulfilling and rewarding life. While some people fully recover and no longer experience psychiatric symptoms, recovery is not about becoming problem free. Everyone has problems from time to time, yet when people have been labeled with mental illness, their problems are often defined as “symptoms,” rather than the normal ups and downs of life. A big part of recovery for many people is stepping away from the “mental patient,” “client,” or even “consumer” identity where we often find ourselves stuck.

- Recovery means I am a full participant in the community and am responsible for my own life.
- Recovery means I no longer think of myself as being “mentally ill,” and instead think of myself as fulfilling roles such as a worker, parent, student, neighbor, friend, artist, tenant, lover, or citizen.
- Recovery means I rely mostly on personal, family, community, and social supports from my culture or my peers rather than getting support solely from the mental health system.
- Recovery means I am prepared to deal with the stresses in my life and view them as opportunities for growth.
- Recovery means becoming so skilled and prepared regarding an “issue” that I no longer have to cope with it because it is no longer an issue.

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<sup>4</sup> *National Consensus Statement on Mental Health Recovery*. (2006). Rockville, MD: Office of Consumer Affairs, Center for Mental Health Services, Substance Abuse and Mental Health Services Administration, U.S. Department of Health and Human Services. Available from: [www.samhsa.org](http://www.samhsa.org) and the NEC website: [www.power2u.org](http://www.power2u.org).

All across this country, and around the world, organizations of consumer/survivors have been demonstrating the reality of recovery. We are the evidence! The concept of recovery is becoming recognized as an important new way to think about serious mental health problems, treatment, and outcomes, and is slowly being accepted and incorporated by traditional mental health programs. It is now common to hear mental health officials and practitioners talk about recovery. Many mental health professionals are seeking new ways to relate to and work with those who use mental health services. Many are looking for ways to transform their programs to be more recovery focused in meaningful and significant ways.

***Where did this idea come from?***

The roots for this shift toward a recovery orientation in mental health are both broad and deep. Mental health consumer/survivors have been a prime force in promoting the current movement in mental health recovery, drawing on personal experiences, social justice values, civil and human rights, and powerful passion to change the mental health service system. Another influence has been the emergence and acceptance of a variety of self-help and 12-step programs, such as Alcoholics Anonymous. These programs provide an opportunity for people with addictions and other kinds of personal difficulties to come together as peers with shared experiences and to help each other.

***Is recovery in mental health the same as recovery from addiction?***

No. There are some similarities, but there are also some fundamental differences in the concepts of substance abuse recovery and mental health recovery.

For example, one of the core differences centers around the issues of power and powerlessness. A common requirement in 12-step programs is to admit powerlessness and turn one's self and life over to the power and direction of a trusted "other" or Higher

*Mental health consumers/survivors have been a prime force in promoting the current recovery in mental health movement.*

Power. While respecting the importance of spirituality for many people, in mental health recovery there is also emphasis on empowerment and self-determination — helping individuals to find their own voice and to take personal responsibility for their own lives. This is based on the belief that individuals need to reclaim, not turn over, their power as one of the first steps of a recovery process.

Another important difference is that in traditional 12-step programs, members are encouraged to label themselves as their addiction or disorder: I am an alcoholic, an addict, and so forth. In mental health recovery, there is emphasis on helping individuals to move beyond the diagnostic labels that have been applied to them by service providers and even themselves. In mental health recovery, individuals are encouraged to NOT identify themselves or allow themselves to be identified by others in any way that makes a medical diagnosis their most salient or defining characteristic.



Being labeled with a diagnosis of a serious mental illness often carries with it an experience of internal and external stigma and oppression. Often the labeled person is portrayed as incapable of managing his/her own life or playing a meaningful role in society. Therefore, shedding the identity of mental illness and adopting an identity of citizen is an important component in recovery. At the same time, it is important to keep paramount the concept of the right of each individual to label one's experience in one's own way, and not prescribe to anyone what his or her recovery might be like.

***Is there any research on recovery?***

You bet! The anecdotal database of individual stories about personal recovery has been substantiated by the findings of research conducted by Courtenay Harding and her colleagues on the longitudinal course of schizophrenia.<sup>5</sup> The research has confirmed and amplified the findings of other international studies: the majority of people diagnosed with schizophrenia can and do recover!<sup>6</sup>

Currently there is a range of research on recovery underway in the United States, Canada, and internationally, with calls for more vigorous efforts to support studies in this area.<sup>6,7</sup> Jean Campbell of the University of Missouri has been conducting well-crafted studies of peer support and consumer-operated services and programs (COSP) for a number of years. For example, the SAMHSA-funded COSP Multi-Site Research Initiative (1998-2006) found that consumer/survivors experienced significant improvements in wellbeing as a result of participation in peer-run services.<sup>7</sup>

***Are these ideas reflected in mental health policy?***

Yes. Recently there have been a number of significant policy documents that support and promote transformation toward a recovery orientation within the mental health system. In 1999, the U.S. Surgeon General issued a report on mental health that, for the first time on a national scale, recognized the importance of recovery in adult mental health. It stated “the concept of recovery is having substantial impact on consumers and families, mental health research, and service delivery.”<sup>8</sup>

*The New Freedom Commission's final report mandates mental health services to be consumer-driven and recovery oriented. We understand what that means. We are the heart of transformation.*

In 2003, the final report of the President's New Freedom Commission on Mental Health (NFC), *Achieving the Promise: Transforming Mental Health Care in America*,<sup>9</sup> called

<sup>5</sup> Harding, C. M, Brooks, G. W., Ashikaga, T., Strauss, J. S, Brier, A. (1987). The Vermont Longitudinal Study of Persons with Severe Mental Illness II: Long-term outcome of subjects who retrospectively met DSM-III criteria for schizophrenia. *American Journal of Psychiatry* 144 (6), 727-735.

<sup>6</sup> See for example the work of Courtenay Harding, John Strauss, Michael DeSisto, and Richard Warner among others.

<sup>7</sup> Campbell, J., Lichtenstein, C., Teague, G., Johnsen, M., Yates, B., Sonnefeld, et al. (2006) The Consumer Operated Service Programs (COSP) Multisite Research Initiative: Final Report. Saint Louis, MO: Coordinating Center at the Missouri Institute of Mental Health. For more information: [www.cstprogram.org](http://www.cstprogram.org). See also: Clay, S. (ed.) (2005). *On Our Own Together: Peer Programs for People with Mental Illness*. Nashville, TN: Vanderbilt University Press.

<sup>8</sup> U.S. Department of Health and Human Services. *Mental Health: A Report of the Surgeon General*. Rockville, MD. 1999, p. 97. DHHS Pub. No. SMA-03-3832. Rockville, MD. Available: [www.mentalhealth.samhsa.gov](http://www.mentalhealth.samhsa.gov).

<sup>9</sup> New Freedom Commission on Mental Health, *Achieving the Promise: Transforming Mental Health Care in America. Final Report*. DHHS Pub. No. SMA-03-3832. Rockville, MD: 2003. Available at [www.mentalhealthcommission.gov](http://www.mentalhealthcommission.gov).

for recovery to be the “common, recognized outcome of mental health services.” The report stated unambiguously, “The goal of mental health services is recovery.”

The term “transformation” was specifically used by the Commission to reflect its belief that mere reforms to the existing mental health system are insufficient. “It is time to change the very form and function of the mental health delivery service system to better meet the needs of the individuals and families it is designed to serve.” The NFC final report mandates mental health services to be consumer driven and recovery oriented. We understand what that means. We are the heart of transformation.

A Consensus Conference on Mental Health Recovery, sponsored by SAMHSA, released a consensus statement on mental health recovery in February 2006.<sup>10</sup> Over 110 persons participated, including mental health consumers, family members, providers, advocates, researchers, academicians, managed care representatives, accreditation organization representatives, and state and local public officials.

The final consensus statement provides the following ten fundamental components of mental health recovery that serve well as guideposts for recovery-oriented service providers, policy makers, and advocates. A full copy of the statement is provided in Appendix C.



Ten Fundamental Components of Mental Health Recovery	
<i>Self-Direction</i>	<i>Strengths-Based</i>
<i>Individualized and Person-Centered</i>	<i>Peer Support</i>
<i>Empowerment</i>	<i>Respect</i>
<i>Holistic</i>	<i>Responsibility</i>
<i>Non-Linear</i>	<i>Hope</i>

These values and principles form the bedrock on which recovery-oriented programs stand. For consumer organizations, they frame our primary “reasons for being” and can help to guide our programs, advocacy work, and decision-making of all kinds.

***What is the role of consumer/survivors in transforming the service system to be more recovery oriented?***

It is up to us, those with the lived wisdom, to keep the spirit and meaning of recovery alive and to be a true force for positive, productive transformation of the mental health

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<sup>10</sup> National Consensus Statement on Mental Health Recovery. Health and Human Services, Substance Abuse and Mental Health Administration, Center for Mental Health Services. Available online at the NEC website: [www.power2u.org](http://www.power2u.org) and directly from SAMHSA’s website: [www.mentalhealth.samhsa.gov/publications/allpubs/sma05-4129/](http://www.mentalhealth.samhsa.gov/publications/allpubs/sma05-4129/)

service system. In the past, the focus and goal of mental health services was on managing symptoms and reaching a level of maintenance.

Through advocacy, direct action, and education by the consumer/survivor movement, those who receive mental health services are coming to have higher expectations of the system and can foresee recovery as an outcome for themselves. Those having a higher personal expectation continue to push the system to this higher vision. This shift has been the result of recognizing the lived wisdom and the right of consumers to shape the services they are receiving.

*It is up to us, those with the lived wisdom, to keep the spirit and meaning of recovery alive.*

The New Freedom Commission's mandate for recovery-focused, consumer-driven services is an opportunity to create a new paradigm in mental health care. It is time to move beyond the clash of "them" versus "us", to come together, learn from one another, and acknowledge that all of us share a common humanity. It is time to recognize that it is not just the individuals receiving services who are moving toward recovery. The system itself must also go through a process of recovery, transforming from policies and practices that are focused on pathology to a system that is recovery oriented and encourages and supports each individual to flourish.

As the concept of "recovery" gains traction, however, there is also a risk that recovery principles and practices will become watered down and meaningless. It has happened before. Consider the terms "empowerment" and "peer support." Consumer/survivors use the word "empowerment" to mean that people who use mental health services make choices, control their own lives, and accept responsibility for their choices and decisions. True empowerment means a reversal in the power structure of traditional mental health service delivery, so that people can no longer be forced to do things against their will.

The word "empowerment" is often stripped of much of this meaning, as mental health services claim to "empower" their clients while still retaining much or all of the decision-making power. When service providers talk about providing "empowerment services" or "empowering" their clients, they reveal a lack of understanding about the basic concept. Empowerment is something that comes from within an individual. No one can "empower" someone else, although certainly others from the community or family can provide environments that facilitate empowerment. When we assist people to become empowered, we assist them to find their own voice, to make their own decisions, and to take personal responsibility and be accountable for finding their own pathways to recovery.

Similarly, the term "peer support" originally meant people helping one another to achieve their own goals. Peer supporters, whether volunteer or paid, were there to assist and encourage people to define what they wanted in life and to help them to advocate for themselves. Peer supporters were also meant to function as role models,

showing others that it is possible for people who have been diagnosed with mental illness issues to live fuller and more satisfying lives.

Unfortunately, in many mental health programs today, people who are called “peer supporters” are used to encourage and even enforce the system’s goals rather than those of the individual. When “peer supporters” are part of a team that stresses compliance with treatment as the primary value, they are not able to provide true peer support, which means people working together to achieve self-defined goals.

Now, as the mental health system moves to incorporate a recovery focus into its programs and practices, some people are being defined as being “not ready to recover” or “in recovery” indefinitely. In some ways, this is simply giving new words to a familiar concept: “Having a *lifelong condition* for which the best possible outcome was maintenance.” This approach does not acknowledge that people can and do recover, so people stay stuck.

It should also be noted that we often hold pre-designed concepts of recovery, empowerment, self-help, and peer support, which may not translate as relevant to persons of color. In the past, mental health systems and even the client movement have gone out to communities of color with a “tool box” approach (We know what you need, and its recovery!), without determining the cultural coping skills that may already be in place. Our biggest challenge is to avoid bringing something pre-created to communities of color and expecting them to accept it without helping design it. We need to find out what has worked in their communities and what is relevant to them.

Recovery is more than being in a state of “remission” or “maintenance.” Recovery is about moving out of the role of patient or client and moving into the more valued and satisfying social roles of student, worker, parent and citizen.

It means being active members and participants of the communities and the culture in which we live.

*Many of us have found that social action is an integral part of our recovery.*

***So, getting involved as a consumer/survivor really makes a difference?***

Absolutely! Not only does our involvement help to change the mental health service system, but it can be helpful for our own personal recovery as well. The very act of becoming involved in helping to transform the system has proven to be personally transformative for many of us.

Joining others who share a common history and finding strength in a collective endeavor helps shift the perception of helplessness and hopelessness. Coming together as a group to find, express, and amplify our voices, to make constructive changes in our communities as we help influence policies and shape services, is empowering. Involvement in activities that positively impact people with mental health issues helps shift our perception of what is possible for us as individuals as well as for us as a group.

Many of us have found that social action is an integral part of our recovery. Finding a group of like-minded people, finding a purpose/meaning/mission, finding that we really CAN do it, that we are needed and wanted, and that we do have something to offer and contribute, provide the very foundation of recovery. We shift from isolation into an arena where we are part of something greater than ourselves, where we are in relationship with others, where we feel connected and valued. This changes our self-perception from one of a person with an incurable “disorder” who is incapable of a meaningful social contribution to one who can participate in purposeful involvement and find a place of belonging.

The cyclic and intertwined nature of empowerment, action, and peer support integral to consumer-run endeavors, illustrates some important components of recovery. Most consumer-run statewide organizations have found that creating a balance between engaging in social action and developing peer support is challenging, but crucial. Both are essential ingredients to building an effective statewide presence and to the recovery process.

The members of the Recovery Consortium know that people recover in their own ways and in their own time. Being involved in a statewide consumer network provides many individuals with opportunities for finding meaning and purpose, developing new skills, sharing with others in peer support, and influencing change through social action.

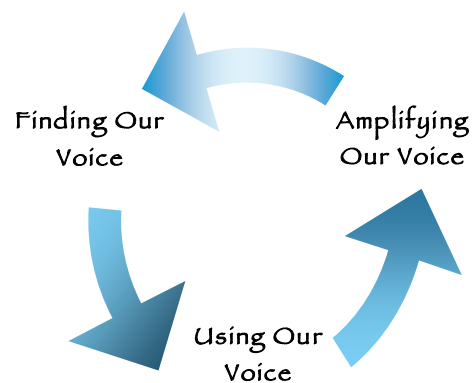
## FINDING AND USING OUR VOICE

In addition to recovery, another core tenet of the consumer/survivor movement is the theme: “Nothing about us without us.” We need to be at every table, not just in treatment team meetings or social activity planning, but also as laws are made, when policy is discussed and decided, while funding is allocated, and where education is delivered.

The consumer movement could be viewed as an ongoing process of finding and using our individual and collective voice. It is a three-part process:

- Finding our individual voice.
- Knowing how to use our voice.
- Amplifying our voice by joining and using the power of the collective voice of many.

Finding and using our voice does not always come naturally or easily. Many of us have learned that our voice doesn’t matter, or we believe that we have little to offer, especially in “important” things such as mental health policy and legislation, funding services or programs, educating mental health workers and community members, or in supporting



and learning from each other. Sometimes we use our voices in ways that turn others away from our message and we feel even more angry, frustrated, or alone.

Consumer/survivors often benefit from training in how to find and use their voice effectively. There are a number of excellent resources for doing this. NEC's manual ***Finding Our Voice*** is a way to facilitate Step One: Helping consumers find their individual voice. This guide provides ideas that consumer leaders can use to help find the voice within which allows them to affect the world around them.<sup>11</sup>

Once consumer/survivors have discovered their voice as individuals, they can profit from taking the next step: knowing how to use their voice. The Consumer Organization and Networking Technical Assistance Center's (CONTAC) ***Leadership Academy*** provides training in important skills in learning how to use one's voice, such as identifying issues, developing goals, planning action, and conducting effective meetings.

Both NEC and CONTAC are national technical assistance and training organizations that have received funding from SAMHSA to develop and offer these educational resources. For more information on these programs, contact NEC and/or CONTAC.<sup>12</sup> Other resources are listed in Appendix A of this manual.

*This manual is designed for those who have found their voice, are learning to use it, and want to learn how to work together to amplify their voice at a broader level.*

## ABOUT THIS MANUAL

*Voices of Transformation: Developing Recovery-Based Statewide Consumer Organizations* is a product of the collaboration of four established and successful statewide consumer organizations known as the Recovery Consortium and NEC. In order to help new organizations avoid “reinventing the wheel,” it was decided to share the wealth of often hard-won knowledge and experience gained by these four statewide organizations.

Members of the Recovery Consortium, as well as other established and emerging statewide consumer organizations, were interviewed extensively, and this information forms the basis for the manual. Consortium members also drafted sections of the document describing their programs. National Empowerment Center staff and consultants have done the final writing, editing, and compiling of the manual.

This manual is designed for those who have found their voice, are learning to use it, and want to learn how to work together to amplify their voice at a broader level. It is

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<sup>11</sup> For more information on *Finding Our Voice* Training, contact NEC at 599 Canal Street; Lawrence, MA 01840; 1-800-POWER2U or 978-685-1494; [www.power2u.org](http://www.power2u.org).

<sup>12</sup> CONTAC. West Virginia Mental Health Consumers' Association, 910 Quarrier Street, Suite 419; Charleston, WV 25301; (888) 825-8324 x20 (toll free); [www.contac.org](http://www.contac.org).

also for those who wish to encourage or support this process. It provides information about how several successful statewide networks formed, grew, met challenges and obstacles along the way, and developed strategies to sustain their organizations financially as well as politically.

While each of the Recovery Consortium organizations has some unique circumstances and experiences, there are a number of important commonalities which can inform statewide consumer organizations at all stages of development — from “just an idea” to an established, successful not-for-profit corporation offering and supporting consumer-operated services and programs.

Some of the people and organizations that will find this manual useful include consumer groups seeking to form a statewide presence, those wishing to add new programs, consumer organizations going through transition, and those existing statewide organizations looking for guidance on avoiding pitfalls, conducting effective meetings, handling conflicts, or dealing with personal agendas, among other topics.

The manual is organized into several distinct sections.

- The Introduction describes the purpose of the manual, provides some of its background and context, and discusses the concept of mental health recovery.
- Part I of the manual outlines the purpose and background of the Recovery Consortium and tells the story of the formation and development each of the four member state-wide organizations that comprise it.
- Part II presents the diverse and inspiring activities and programs sponsored by each organization.
- Part III identifies some of the principles of success that are common to these organizations.
- Part IV offers a step-by-step guide to creating a statewide consumer organization.

Because there is a wealth of excellent information available about many of the topics discussed in the manual, Appendix A includes resource information so that readers can delve more deeply into areas of particular interest or need.



## A WORD ABOUT WORDS

At the onset it may be helpful to clarify some of the terminology used in the manual. Language is important because the words we choose to use communicate many subtle things about our attitudes and assumptions. They carry more meaning than just what is seen or heard on the surface. Because of this, words can be highly contentious, and the selection of words for a public document carries significant weight.

The authors of this document had a number of conversations about what terms to use, and while we came to a practical agreement, there are still deeply felt differences of opinion. We are sure our readers will have their own preferences for terminology and concerns about our decisions. The following discussion presents some of the words we've chosen to use and why we chose to use them.

Many people who have a difficult time emotionally, psychologically, spiritually, and mentally look to the mental health system for help and hope to end their suffering. The experience they are having is diagnosed and referred to as a “mental illness.” Those people with ongoing mental health issues are referred to in many ways. They are referred to as having “serious mental illness,” “mental disorders,” “psychiatric disorders,” or “disabilities.” Emerging terminology includes “psycho-spiritual overwhelm” and “emotional suffering” to describe a person’s experience.

Some time ago, people who have a current or past experience of being labeled with a “mental illness” and/or have used mental health services agreed to be known as a movement of “Consumers/Survivors/Ex-Patients” (sometimes shortened to c/s/x). Not all people who share this experience like or agree with this title. Some call themselves “clients,” some “psychiatric survivors,” and others prefer to be known as those with “psychiatric disabilities.” But let’s not forget, that first and foremost, we are all “people.”

*The authors of this manual use various terminologies according to the context. We encourage each individual to use the terms that feel right and accurate to describe your own experience.*

However, there does seem to be a consensus that the movement of people who use or have used mental health services and who seek to have a voice in shaping those services shall be called the “consumer/survivor/ex-patient movement,” or sometimes simply the “consumer movement.”

While we believe it is the right of each individual to label one’s own experience in one’s own way, this document generally uses the term “consumer/survivor” to mean anyone who uses mental health services in the present or who has in the past, those who feel they have survived psychiatric services, and those who consider themselves ex-patients.



Other terms that need clarification are consumer networks, coalitions, and organizations. Although these terms are often used interchangeably, there is a difference.

- **NETWORK:** A network is a formal or informal connection of already established independent groups, centers, or organizations, such as a network of peer drop-in centers.
- **COALITION:** Coalitions are a coming together of different groups or organizations that may have very different missions and may not all be consumer owned and operated, but share a particular common interest. In a coalition, groups agree to work on a specific issue, even when they may disagree on other issues. Each member of a coalition continues to maintain its independent existence, but within the coalition the groups work together toward the goal.
- **ORGANIZATION:** A consumer-run organization is generally a group of consumers who have come together to create a standalone, consumer-owned and -run entity. They form for a specified purpose, develop a leadership structure, generally establish a not-for-profit corporation, and hire at least a few staff people to manage the business.





## *PART I*

# **WHO WE ARE: THE RECOVERY CONSORTIUM AND ITS MEMBERS**

This section describes the Recovery Consortium and its members. Each organization discusses its history, including some of the circumstances and factors that led to its creation and how it has developed or changed over time. The descriptions also provide information about how the organizations are structured, their staffing, and funding. The last section identifies some of the important structural and philosophical commonalities that these four diverse organizations share and which they believe have contributed to their success and sustainability over time.

## **WHAT IS THE RECOVERY CONSORTIUM?**

What would it look like if organizations came together to share information and resources on recovery? How much more could be accomplished if organizations did not have to duplicate efforts? The National Empowerment Center, Inc. (NEC) has always promoted the values of self-help, empowerment, and recovery, and has a rich history as a catalyst for innovation in the mental health field. In keeping with that tradition, NEC envisioned the possibility of collaboration and cooperation between recovery-oriented agencies and organizations. The Recovery Consortium grew from this vision.

The Recovery Consortium is composed of four statewide consumer organizations that have performed valuable work in their states and are now sharing and disseminating information and resources on recovery to a national audience. This collaborative effort is designed to offer insights gained from experience, to provide technical assistance, and to share resources to help others to sustain their organizations through changing times.

The four statewide organizations that form the Recovery Consortium are:

- California Network of Mental Health Clients
- Ohio Advocates for Mental Health
- On Our Own of Maryland, Inc.
- Vermont Psychiatric Survivors

Each of these groups has existed for many years. All of them have gone through challenges and changes. All of them have been successful in creating exciting and innovative ways to bring the message of recovery to consumers and survivors within their state. Although these four organizations are not the only successful statewide organizations, we hope their experiences will be useful to all statewide organizations and to those working to start new ones.

NEC is the convener and coordinator of the Recovery Consortium. Together with the four statewide organizations, NEC produces and disseminates information, such as this manual, to assist consumer/survivors and their organizations around the country to thrive and expand. NEC coordinates the consultation to local groups to assist in their development, and serves as a focal point for the Consortium's work, which includes technical assistance to developing consumer organizations.

### CALIFORNIA NETWORK OF MENTAL HEALTH CLIENTS

*The California Network of Mental Health Clients* (California Network) started in 1983, with its roots in a long history of activism in the state. Older organizations, such as the Network Against Psychiatric Assault (NAPA), and the publication *Madness Network News*, had existed in California since the mid-1970s. These groups did not call themselves “consumers,” but used more radical and confrontational terminology like “psychiatric inmate,” and they did not cooperate with the mental health system in any way. In fact, when a local activist became part of a statewide Citizens’ Advisory Council appointed by the California

Department of Mental Health, some people considered this to be “selling out” or “consorting with the enemy.”

In 1982, the Citizens’ Advisory Council held a conference on the Year of the Consumer. While some of the speakers were consumers, the keynote presentation was by a provider. Out of that conference came a resolution, spearheaded by some of the consumers who attended, that there was a need for a statewide consumer organization. The Consumer Steering Committee (the precursor to the *California Network*) was formed the following year. The *California Network* was formally incorporated as a not-for-profit corporation in 1984.

The older groups were very opposed to formal structures and hierarchies, and in the early years of the *California Network*, it operated in the same loose manner. There was a reluctance to give anyone a title or to say that a particular person was in charge of anything. Rather than having an executive director, one person was called the “administrator,” but there were no clear lines of authority.

The *California Network* developed action plans in several areas including public policy, medication, self-help, governance and structure, stigma and discrimination, and



cultural competence (originally called diversity). There was a strong feeling of caring, companionship, and sense of community among members of the group. Relationships and personal connections were very important. The organizational structure was non-hierarchical; everyone had a voice and there was no single authority. Decisions were made by consensus. If someone was strongly against something, the group kept talking about it until they could come to a common position, or the issue was dropped.

Consensus can be a more difficult way to make policy than voting, where the majority wins and the minority loses, but it ensures that every voice is heard and that the organization doesn't move in a particular direction unless everyone is in agreement. The organization was governed by a Board of Directors, which was elected statewide. The primary source of funding was the California Department of Mental Health, although funds to support special projects came from other sources, such as Community Support Program and a local foundation, the Zellbach Family Foundation, which provided support for the *Reaching Across* books.

*Consensus can be a more difficult way to make policy than voting, where the majority wins and the minority loses, but it ensures every voice is heard.*

In its first eight or nine years, the *California Network* was extremely productive, energized by a common mission and goals. During this time, the Network:

- Produced two successful and widely circulated books, *Reaching Across* and *Reaching Across II*, which had chapters written by many state and national consumer leaders.
- Conducted the Well Being Project, possibly the first consumer-directed research project in the country. The Well Being Project also produced a film and companion book, entitled “*People Say I’m Crazy*. ”
- Expanded committee work groups into active self-help, public policy, and minority projects.
- Spurred the passage of legislation such as a law requiring that there be two clients on each mental health board (since updated to require 50 percent client/family member representation).

However, as time went by, the lack of formal leadership made it difficult to continue the sense of common purpose. In addition, conditions were changing around the state, based largely on what the *California Network* had accomplished. There were large numbers of local support and self-help groups. In time, the Board of Directors of the *California Network* was composed of clients who were not previously acknowledged leaders, yet had been active on the local level. The predominant needs of the organization were shifting away from a centralized statewide presence to the need for more local presence.

In addition, the *California Network* was not fulfilling certain obligations required by its state funding. Because of internal disorganization, the *California Network* wasn't spending all the money in the grant. In 1992, the Director of Mental Health told the

*California Network* they had to fulfill the conditions of the contract. Board meetings became contentious. The old spirit of love and cooperation gave way to anger and frustration.

Fortunately, the Consumer Liaison in the California Department of Mental Health supported the idea of a strong grassroots consumer organization. She suggested using unspent grant funds to sponsor and organize a conference, which took place in 1995.

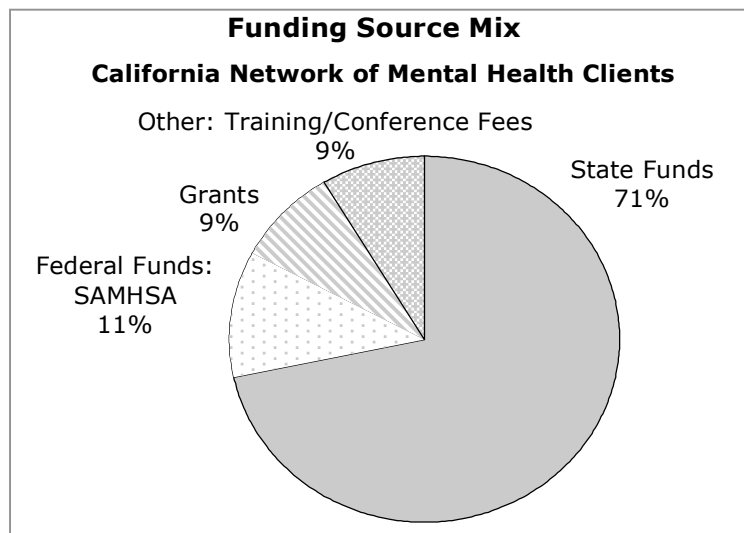
Over 300 people from around the state attended with the purpose of redefining their statewide organization.

*Members identify both its common purpose and the companionship of peers as the foundation of the organization's long-term survival.*

To ensure that everyone's voice was heard, and not just the people who had attended the conference, the *California Network* conducted a survey to reach out to all of its members, many of whom were dissatisfied. The survey asked what they thought the goals, principles, activities, and structure of the organization should be. Based on this input, the *California Network* drew up a reorganization document, which became the new "constitution" for the coming years. The structure, activities, and projects of the *California Network* would be more localized. In addition, it was decided there would be a full-time executive director. New bylaws were developed that formalized the reorganization.

Over the next year and a half, the *California Network* was completely reorganized. The Board of Directors, elected statewide, voted itself out of existence and was replaced by a new Board. Most of the members of the new Board were elected by regions, with only a small proportion of Board members representing the state as a whole. An executive director was hired and is still in that position. The new *California Network* that ultimately emerged was stronger, and the organization embarked on a renaissance.

Currently, the *California Network* has a budget of approximately \$690,000, of which about \$511,000 is state funding, \$70,000 is from a SAMHSA Networking Grant, \$55,000 is from other foundation grants, and the rest from a variety of sources including the annual conference, sales of merchandise,



donations, and fees charged for training. The annual conference is supported by funding from California Protection & Advocacy and the California Department of Mental Health, for all costs of holding the conference that are not covered by fees paid by conference participants.

Recently *California Network* saw a dramatic increase in its total budget as a result of additional state funding from the new California Mental Health Services Act (MHSA). In one year, funding jumped nearly 50 percent; however, it should be noted that all of the activities reported on in detail in this manual were accomplished with the lower level of funding. Due to the recent increase in funding, *California Network* is also undergoing an increase in staffing.

At present, *California Network* hires individuals into the following positions:

- Executive Director
- Administrator/Program Support
- Office of Self-Help/Technical Assistance and Support Center (TASC) Director
- California Memorial Project Coordinator (a half-time position)
- 5 Regional Project Coordinators (each for 6 hours per week)
- Cultural Competency Coordinator (8 hours per week)
- Mental Health Services Act Director (new position)
- 5 Mental Health Services Act Regional Coordinators (new positions)
- Bookkeeper and conference coordinator (contract/consultant positions).

## OHIO ADVOCATES FOR MENTAL HEALTH



The *Ohio Advocates for Mental Health (OAMH)* was formed in 1984-85 with the strong support of the state's Director of Mental Health, who came from an advocacy background and supported the principle of consumer organizing. She provided the initial funding, and for the next three or four years the organization established its presence in the state. Despite very limited funding, OAMH held a conference each year, which was attended by more than 200 people. They participated in statewide mental health planning meetings, and promoted legislation to help people move from institutions into the community.

As more funding became available, *OAMH* hired an Executive Director who is still serving in that position after sixteen years. A statewide 800 number was provided to ensure that consumers from all over the state could communicate with the staff in Columbus. *OAMH* assisted a number of local self-help groups to get started.

*OAMH* also worked to ensure that when people moved from institutions into the community they had real opportunities for better lives. Initially, although the state Department of Mental Health was promoting the idea of deinstitutionalization, many people ended up homeless or in bad living situations, and *OAMH* did significant advocacy promoting good housing and recovery.

Rather than holding their annual meeting in the state capital, Columbus, as had been the practice, the conference was moved to a different region of the state each year, which increased attendance. Currently, about 500 to 600 people annually attend the three-day conference which is packed with workshops and plenary sessions. Almost all workshops are led by consumer/survivors. There is also a pre-conference day that specifically focuses on funding and other issues specific to self-help groups.

*OAMH provides peer support for people in leadership roles, who often are not getting what they need as they support others.*

*OAMH* produces a quarterly newsletter, *The Aurora*, with a circulation of approximately 4,500 (up from 500 at its launch). Focused primarily on legislative issues, the newsletter summarizes actions and events affecting consumers statewide.

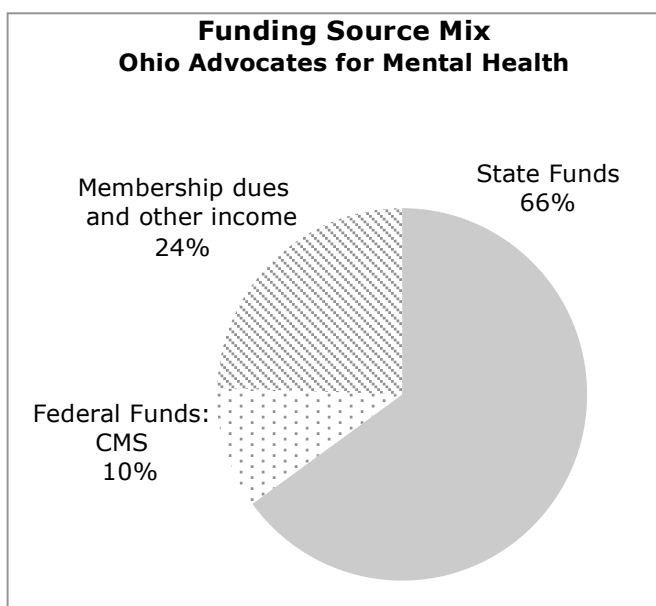
In 2001, *OAMH* received a federal CMHS statewide networking grant, which enabled it to expand technical assistance to local groups. A directory of self-help groups was created and there was increased sharing of resources and information. *OAMH* provides peer support for people in leadership roles, who often are not getting what they need as they support others.



Although the CMHS grant ended in 2003, *OAMH* is continuing to do the networking that they consider so valuable. *OAMH* spends considerable energy supporting local groups that are in constant danger of losing their funding. The organization is run by an 18-member Board that is geographically representative of the state. Ohio has both a number of major metropolitan areas as well as rural areas. *OAMH* is committed to making sure that all parts of the state are represented, as well as working to achieve ethnic representation. Fifteen Board seats are for consumer/survivors; the other three are “professional support seats.”

Professional seats may be filled by providers who also identify as consumers. In fact, two of the seats are currently held by consumer/providers. All officers must be consumer/survivors. Three of the consumer/survivor seats are appointed by the general membership; the remaining consumer/survivor seats, as well as all of the professional seats, are recruited and appointed directly by the Board. Board members are limited to two three-year terms. *OAMH* has six full-time and four part-time employees.

Ohio Advocates for Mental Health has a total budget of approximately \$756,000, of which about \$592,000 is state funding; \$79,000 is federal funding (CMS); and the balance from membership dues and assorted other income. *OAMH*'s budget illustrates how an organization was able to make the transition from one that received the bulk of its funds from federal sources, to other sources when its federal funding was greatly reduced.



*OAMH* employs:

- Chief Executive Officer
- Director
- Associate Director
- Director of Education and Training (part time position)
- Technical Assistance Coordinator
- Advocacy Coordinator
- Administrative Assistant

## ON OUR OWN OF MARYLAND, INC.



The consumer movement in Maryland began in 1981 with the founding of *On Our Own, Inc.*, as a mutual support group for people who had been in psychiatric hospitals. The group began meeting in a church basement in the Baltimore suburbs and then moved several times before settling into the main public library downtown.

The group incorporated the following year and one of their first activities was to coordinate a statewide conference for mental health consumers. They chose the name “*On Our Own*” from the book written by Judi Chamberlin in the late 1970s. *On Our Own*, with the support of a sympathetic administrator in the Maryland Mental Hygiene Administration, used funding from the Community Support Program (CSP)<sup>13</sup> to organize this meeting for Maryland consumers.

One result of the conference was the development of a policy paper calling for changes in mental health service delivery in Maryland, including a recommendation for a consumer-run drop-in center. In 1983, once again using CSP funds, *On Our Own, Inc.*, opened a drop-in center in downtown Baltimore, the first in the country to operate with federal funding.

Planning for an additional drop-in center began that same year by a group of consumers in Montgomery County, a Maryland suburban county just outside Washington, D.C. The second center opened in 1985 as *On Our Own of Montgomery County, Inc.*, in downtown Rockville, Maryland. They were assisted by the Montgomery County government, which leased a building to them for \$1 a year.

With the rapid growth of new consumer support and advocacy groups around the state, a statewide organization, *On Our Own of Maryland, Inc.*, was formed in 1985, and was incorporated as a not-for-profit organization in 1992. Today, *On Our Own of Maryland, Inc.*, through its local affiliate consumer groups, has a presence in every county in the state. *On Our Own of Maryland* has held a statewide conference every year since 1993. The yearly conference attracts three to four hundred people from all over the state.

*On Our Own of Maryland* has always been proud of not allowing state funding to interfere with being a forceful advocate for the rights of patients in Maryland institutions. In 1982, in partnership with the University of Maryland School of Law, *On Our Own of Maryland* conducted a ten-week training on the legal rights of people in psychiatric institutions.

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<sup>13</sup> The CSP was then part of the National Institute for Mental Health (NIMH) and is now within the Substance Abuse and Mental Health Services Administration (SAMHSA)

One result of this project was the filing of a class action lawsuit against the state of Maryland, based on claims that patients in state hospitals had fewer rights than people in the prison system (for example, less access to lawyers and fewer guaranteed legal rights). The suit was filed in the same year the first drop-in center opened. While some people in the consumer movement feared that taking government funding would make the groups less activist, this lawsuit was evidence to the contrary.

The lawsuit was settled in April of 1985 in a federal consent decree that established “rights advisors” in all state psychiatric facilities; established a formal system of grievance resolution; and provided \$500,000 annually to an external legal advocacy agency that provides no-cost legal assistance to patients in these facilities.

In coalition with a number of other mental health organizations, *On Our Own of Maryland* helped to file successful patients’ rights legislation in 1983, 1984, 1985, and 1986. These bills became known as the patients “bill of rights” and applied to any entity receiving state funds including state and private hospitals and psychosocial and residential rehabilitation programs. In 1985, a significant reversal of the state’s policy occurred on seclusion and restraint, which had been considered a form of treatment prior to this legislation.

*In coalition with a number of other mental health organizations, On Our Own of Maryland helped to file successful patients’ rights legislation.*

*On Our Own of Maryland* had received complaints from many consumers and family members that patients were being routinely placed in seclusion for many months and even years in some of the private psychiatric hospitals in Maryland. There was even a documented case of a patient being confined to a specially designed seclusion room for thirteen years at one of these private hospitals, which was justified as “treatment.” *On Our Own of Maryland* is very proud that, in coalition with other advocacy groups, it succeeded in abolishing seclusion and restraint as a “form of treatment.” The law now requires that it can only be used in situations where the person is a danger to self or others.

In 1985, *On Our Own of Maryland* received a contract from the Community Support Program at the National Institute of Mental Health (now CMHS) to host the first national Alternatives conference. This event was held at the College of Notre Dame in Baltimore on June 20-22, 1985 and was attended by over four hundred people, including consumer representatives from Alaska, Hawaii, and Puerto Rico.

*On Our Own of Maryland* opened its official statewide office in 1993 with two staff members, one full-time and one part-time. Today, it has eight full-time and four part-time employees. It has a nationally recognized “Anti-Stigma Project” which focuses on stigma in the mental health system. In March 2001, *On Our Own of Maryland* coordinated and hosted for SAMHSA/CMHS the first “National Symposium to Address Discrimination and Stigma” in the United States, held in Baltimore, MD. The U.S. Surgeon General was one of the keynote speakers at this major event, indicating

that even the medical establishment is becoming aware of the role that consumers and survivors have in providing leadership in defining, recognizing, and addressing stigma and discrimination.

*On Our Own of Maryland*, through its an advocacy training project, conducts specialized workshops in the area of recovery for consumers as well as a separate workshop on recovery for staff members of provider agencies. Workshops are also offered on employment, with special emphasis on the federal “Ticket to Work” Law and its implementation.

The “Olmstead”<sup>14</sup> project, with federal funding channeled through the Maryland Mental Hygiene Administration, is another special project of *On Our Own of Maryland*. This project employs three part-time peer support specialists who work with patients in three state psychiatric hospitals, assisting them with transition back into the community. This program has been so successful there are plans to expand it by having consumer peer support specialists in all state psychiatric facilities.

In 2000, *On Our Own of Maryland* created its own housing development initiative to address the lack of affordable, decent housing for mental health consumers. Today, Main Street Housing, Inc., is a subsidiary

*On Our Own of Maryland created its own housing development initiative to address the lack of affordable, decent housing for mental health consumers.*

corporation of *On Our Own of Maryland* and has purchased housing in Washington and Howard Counties. These houses are rented to mental health consumers who have their own leases, with no requirements that they participate in mental health treatment unless they choose to do so. Main Street Housing is in the process of purchasing additional homes in Harford County this year, with plans to expand into two more counties.

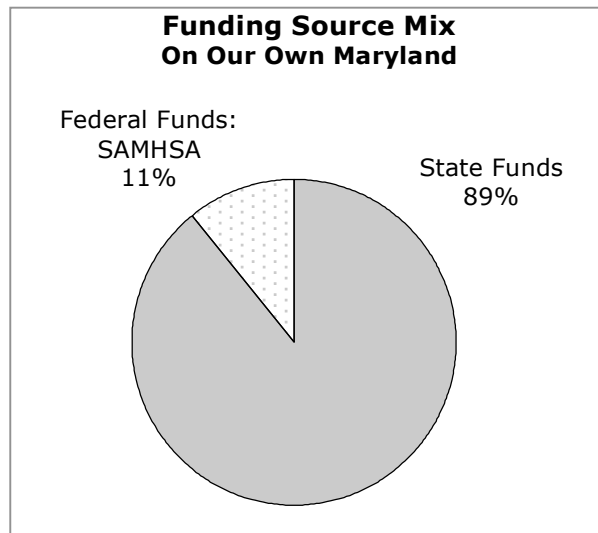
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<sup>14</sup> “Olmstead” refers to a Supreme Court decision that held that it is a form of segregation to keep people in institutions when they are able to live in the community.

The largest source of funding comes from the State of Maryland: \$570,000 (approximately 89 percent), while the other 11 percent comes from the federal Center for Mental Health Services (CMHS) grant.

*On Our Own of Maryland* employs eight full-time and three part-time employees:

- Executive Director
- Director of Training and Communications
- Training Coordinator
- Training Specialist
- State Network Coordinator
- Administrative Assistant/Graphic Designer
- Fiscal Manager
- Main Street Housing Director\*
- Three part-time positions\*\*



\*Main Street Housing, Inc., is a subsidiary corporation of *On Our Own of Maryland, Inc.*, which develops independent housing for mental health consumers throughout Maryland. The Executive Director's position is paid for by a grant to *On Our Own of Maryland*.

\*\*Part-time positions are Peer Support Specialists who work in state hospitals assisting the transition of patients into the community. These positions are funded through an Olmstead grant.

## VERMONT PSYCHIATRIC SURVIVORS



Vermont has had a number of active consumer groups going back to the mid-1970s, and it was out of this history of activism that *Vermont Psychiatric Survivors (VPS)* was born.

In the early 1980s, *VPS* began to obtain state funding, but it took some time for the group to get organized, to incorporate as a fully independent not-for-profit corporation, and to develop a workable administrative structure. At first they had co-directors, but this didn't work well and a full-time director was hired. There was a Board of Directors, which represented all the areas of the state and which ran the organization in consultation with the staff.

*VPS* provides ways for members to get involved, learn leadership skills, and take on more responsibility in the organization. For example, when one executive director decided to move on and pursue another employment opportunity, he looked internally for his replacement. In his role as director, he had been mentoring new leaders and recommended to the Board that they hire a new executive who had come up through the ranks of the organization. They took the suggestion and hired the current *VPS* director, who had been part of a local support group, on the *VPS* board as secretary, and employed as a Recovery Education Coordinator before assuming responsibilities of Executive Director. This is an example of how organizations can empower, mentor, and support individuals to take on new responsibilities and find their strengths as leaders.

The early days of *VPS's* history were marked by controversy. People who had been active in the older groups were concerned that state funding would interfere with *VPS's* ability to represent their interests. This led to picketing at an early organizational meeting and a level of divisiveness that could have ended *VPS's* effectiveness as a consumer organization. However, the *VPS* director took the lead by meeting with the protestors and even at one point carrying a sign herself. She eventually persuaded many of them to come inside and join the meeting. Her action established an important principle of inclusion and ensured that all points of view were recognized and represented within the organization.

*Vermont Psychiatric Survivors* engaged in numerous advocacy campaigns, most notably that surrounding the controversial use of electroconvulsive therapy (ECT) in the state. *VPS* pushed for a legislative study, and people testified at legislative hearings about the experience. The result was a law that requires much more attention to informed consent and recordkeeping around the administration of ECT.

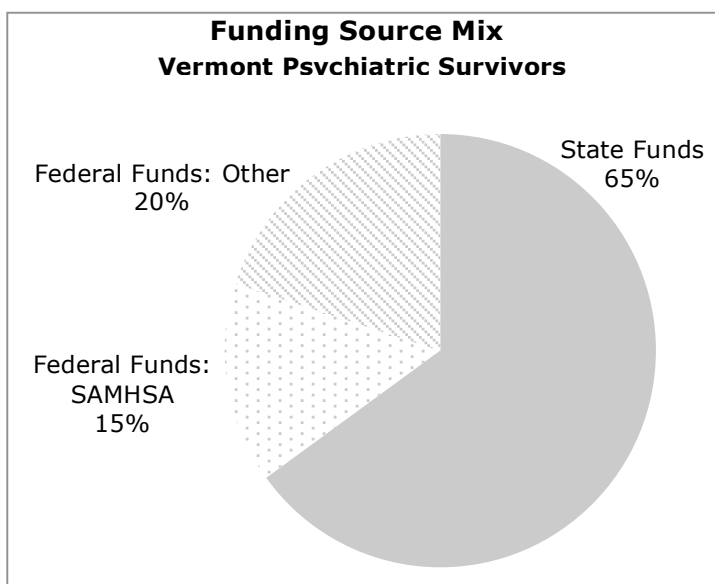
*VPS* publishes *Counterpoint*, a quarterly newspaper that reports on legislative activities and relevant news and controversy, and includes expressive arts and important

resources. This newspaper was established before *VPS* incorporated and is respected as a source of information by mental health providers as well as consumers. Distributed free throughout the state, it has a circulation of approximately 7,000 readers. *VPS* also publishes an online quarterly newsletter, *The Survivor*.

A major concern of *VPS* is fostering new leadership, especially helping newer and younger people to get involved. *VPS* is experienced at mentoring and encouraging new people to take on additional roles as their skills and confidence grow. One important way this happens is through the Recovery Education Program, which offers training at sites around the state every year. This program offers not only information and support to participants in recovery, but provides follow-up opportunities for interested persons to learn more, develop skills as group facilitators, and work as paid recovery educators. Many recovery educators use this program as a launch place for other kinds of leadership roles and employment.

Vermont Psychiatric Survivors has a budget of approximately \$497,000, 65 percent of which comes from state funds, 15 percent from a SAMHSA Statewide Networking Grant, and 20 percent from another federal source, the Department of Housing and Urban Development (HUD).

Currently, there are seven full-time and three additional part-time employees of *VPS*:



- Executive Director
- Administrative Assistant
- Outreach workers (2 positions)
- *Counterpoint* Editor
- Recovery Education Coordinator
- Safe Haven Administrator (Safe Haven is a housing program)
- Three part time peer-support workers at Safe Haven.

## COMMONALITIES AMONG RECOVERY CONSORTIUM MEMBERS

Reflecting differing local conditions, each organization in the Consortium has developed somewhat differently. Both California and Vermont, for example, have long histories of independent organizations that predated the formation of the statewide group, and in both cases had to work to include people who felt left out.

The four groups also vary in factors such as geography and population. California is an enormous state with a large population, while Vermont is a mostly rural state with a small population. However, it is clear from looking at the groups' histories, that they share a number of characteristics and beliefs.

Many of the commonalities found among the Recovery Consortium can also be found as “common ingredients” of consumer-operated services and programs, researched by Jean Campbell as part of the Consumer Operated Services and Programs (COSP) Multi-site Research Initiative (1998-2006), funded by SAMHSA.<sup>15</sup>

### ***Grass-roots Representation***

All of these groups share basic beliefs about the importance of *grass-roots representation*. They were all formed to ensure that people who are receiving or have received mental health services represent their own interests, rather than having other groups speak “for” them. And all of the Consortium organizations take on issues that are important to their members, doing so even when it means opposing their own funding agencies.

### ***Focus on Recovery***

All of these organizations have a strong *focus on recovery* and provide numerous opportunities for their members to become involved in individual recovery (through support groups, for example), as well as promoting recovery for others.

### ***Organizational Independence***

Each of these groups also illustrates the importance of achieving *independence* as an organization, even if this takes place over a period of years. Becoming incorporated, getting nonprofit status from the IRS, and having a Board of Directors to govern the organization are all ways for an organization to control its destiny.

### ***Purpose and Focus***

Each of the organizations has a *purpose*: anti-stigma, recovery education, development of support groups, community education, and policy formation, to name a few. The goal or focus may change over time, and serve as a unifying force that gives direction and energy to the group.

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<sup>15</sup> For more information about “common ingredients” and research into consumer operated programs, see: Clay, S. (ed.) *On Our Own Together: Peer Programs for People with Mental Illness* (2005). Nashville, TN: Vanderbilt University Press.



### ***Education***

Also common to each is the use of *educational approaches* as part of outreach strategy and credibility building. Each organization has sought to educate consumers, mental health system workers, legislators, funding institutions, and the general public about the wider issues effecting mental health consumers, about the lived wisdom of the consumer movement, and about the reality of recovery for those with mental health issues.

### ***Inclusiveness***

Finally, as each of these organizations moved from informal structures to more formal ones, each continued to be as inclusive as possible. The organizations work hard to draw in people representing the broad range of those who use or have used mental health services, and to make sure that there are structures in place so that minority points of view can be heard.





## PART II

### WHAT WE DO: SELECTED PROGRAMS AND ACTIVITIES

There are many different ways and models of promoting recovery and every organization chooses its activities and programs based on values and needs, as well as opportunities. In Part I, the histories of the four statewide consumer/survivor organizations in the Recovery Consortium were described and areas of commonality in structure and values were identified.

This section examines the kinds of activities and programs offered by these organizations. Not only is the number of these initiatives impressive, but they also represent activities that are diverse, creative, and wide-ranging. These inspiring organizations demonstrate that there are many ways that consumer organizations, networks, and coalitions can put recovery principles into operation.

#### CALIFORNIA NETWORK OF MENTAL HEALTH CLIENTS



##### *Coalition Building*

The *California Network* has been very successful at working with a wide range of mental health and other organizations. Coalitions are important because they build on the strengths of all the members of the coalition as they work toward a common goal. In a coalition, groups agree to work on a specific issue, even when they may disagree on other issues. Each member of a coalition continues to maintain its independent existence, but within the coalition, the groups work together toward the goal.

The most dramatic example of a successful effort by a coalition is the passage in 2004 of Proposition 63, the Mental Health Services Act. This came about through a broad-based mental health coalition which included the *California Network*, the California Council of Community Mental Health Agencies, the Mental Health Association, the California Association of Social Rehabilitation Agencies, the California Alliance for the Mentally Ill, United Advocates for Children of California, the California Mental Health Directors' Association, the Service Employees International Union, and government-based organizations such as the California Planning Council.

This coalition, formed in 2003, is composed of groups that have numerous differences and represent many different stakeholders. They joined together because they saw a need to bring new money into the mental health system. Proposition 63 was created to fund innovative, community-based services by imposing a 1 percent tax on incomes over \$1,000,000. Because of client involvement, the draft text of the Proposition included language about the recovery vision, self-determination, and the necessity for peer support.

At its 2003 statewide conference, the *California Network* discussed working on the document that was to become Proposition 63. Some members were concerned that more money for mental health services might just mean more of “the same old thing,” but after much discussion at a membership meeting, the proposition was approved as the *California Network*’s number one public policy priority. *California Network* members were pleased that the Proposition would support only voluntary services, and that it promoted holistic services that addressed the real-life needs of clients. The Proposition also included clients and their expertise in its provisions regarding workforce development, training, and educational programs. Members especially liked the idea that 5 percent of the funds raised were to be set aside for “innovative programs” which support the emerging best practices of self-help programs.

To get the issue on the ballot, signatures had to be collected from every county in the state. Many *California Network* members joined their coalition partners in this effort, the first time many of these individuals had ever participated in this kind of grassroots political activity. After the Act became a Proposition on the ballot, *California Network* members became equally active with their coalition partners in promoting it to the public.

*The California Network used its involvement ... to show that people who used mental health services weren't just people who "needed help," but were actively involved in determining the kind of help they wanted.*

The *California Network* used its involvement in this phase to be sure that other supporters didn't use negative stereotypes to promote the proposal. They wanted to show that people who used mental health services weren't just people who “needed help,” but were actively involved in determining the kind of help they wanted. They also wanted to make sure that the Proposition wouldn't use the myth of the “violent mental patient” to promote its passage. Although the governor opposed the measure, as did most of the major newspapers, it passed with 53 percent of the vote.

The *California Network* is now hard at work on the next phase, which is implementation. The state has been developing regulations for the program, and the *California Network* has been actively involved in ensuring that these regulations carry out the spirit and letter of the original proposition. The *California Network* has produced position papers in response to specific state regulations, and has been an active participant in developing the regulations.

As this new law begins to fund services, the *California Network* is actively monitoring the process to be sure that the goals of promoting voluntary, supportive services are achieved, and that a fair share of the funding goes, as intended, to programs designed and operated directly by clients.

Another example of a successful coalition is the work the *California Network* did with the Service Employees International Union (SEIU), which represents mental health workers in state hospitals and community mental health programs. Although there are many issues on which workers and clients disagree, they worked together on a bill to reduce the use of seclusion and restraints, which was passed in 2003. The two unlikely partners in this cause held focus groups of workers and clients across the state, and developed a joint public statement in support of the reduction of restraints and seclusion. As a separate organization, the *California Network*'s position was stronger than the joint statement; nevertheless the *California Network* could agree to all of the points of the joint statement.

Like several of the other organizations described in this manual, the *Network* has also been an active participant in statewide cross-disability coalitions.

### ***Client Culture***

Every year the *California Network* chooses a Cultural Competency project as an activity. One of these projects was the development of a training curriculum on the concept of client culture. While it is now generally accepted that the cultures of various ethnic groups and other special population groups

*Client Culture: Mental health clients have values, beliefs, and lifestyles that are molded as a result of their personal experiences of a mental disability, the mental health system, and their own ethnic culture. When these personal experiences are shared, mental health clients can be understood better and empowered to effect positive system change.*

need to be recognized and supported so that services can be provided that are relevant to people's needs, the concept of a "disability culture" is not as widely known.

The *California Network*, with support from the California Department of Mental Health's Office of Multi-Cultural Affairs, conducted focus groups to ask clients to define "client culture," and whether it is useful to have a designated group culture for clients. These focus groups were held in each region of the state and resulted in a report. Trainings on client culture were then conducted throughout the state, and eventually the Department of Mental Health added a definition of client culture, and a mandate that every county have trainings on it, as part of its overall cultural competency managed-care requirements.

The following were the topic headings incorporated in the required training:

- Impact of system mechanisms on quality of life
- Diagnosis/labeling
- Medication
- Hospitalization
- Societal/familial stigma
- Economic impact
- Housing
- Culturally and linguistically inappropriate services
- Forced treatment.

The primary audiences for the trainings are program administrators and service provider staff. It is vital that those who determine policy and those who implement programs and services have an in-depth understanding of the impact that receiving a diagnosis has on a person's life.

Accessing services from the public system also carries with it a monumental set of hurdles that each client must face and conquer in order to receive any of the positive factors that may be available. As every public system strives for culturally appropriate delivery of programs and services, the system's personnel training programs must include knowledge that recognizes the needs of the clients as an identified collective.

The *California Network* also presents the Client Culture training to established client-run and emerging mutual support groups. The emphasis for this audience is to assist clients in self-recognition, empowerment, and recovery goals. The following sections, while not in the training mandate, have been added to the presentation:

- Personal empowerment
- Steps to wellness
- Self-help
- Peer advocacy and support
- Education
- Alternative mental health services
- Holistic health
- Political activism
- Collaboration/partnership for system change.

***Legislative Activity: Neutralizing the Expansion of Involuntary Out-Patient Commitment in California***

The *California Network* has had an active Public Policy Committee throughout its history, which has taken on a number of issues. Beginning in 1998, several initiatives were raised in the California legislature to expand involuntary treatment and/or pass an

involuntary out-patient commitment (IOC) bill. These initiatives would allow people living in the community to be forcibly treated, usually in the form of being given psychiatric drugs against their will.

The *California Network* chose to define the issue as opposing the *expansion* of forced treatment, as a way of finding common ground among California clients and unifying them, since some members of the *California Network* supported the existence of involuntary treatment in limited emergency situations. However, it was clear that there was consensus to oppose *any expansion* of forced treatment. Even people who supported the existence of limited involuntary treatment didn't want to see it increased, and everyone agreed that there were alternatives to forced treatment which needed to be supported.

*The California Network wrote position papers, and members were quoted in newspapers, as well as appearing in the editorial pages.*

Although initially the *California Network* was not as visible as the supporters of IOC, particularly NAMI-California and the California Psychiatric Association, it quickly became more skilled, more sophisticated, and more visible. A yellow T-shirt with the slogan, "Those that cannot remember the past are condemned to repeat it," with an inverted black triangle symbolizing the 250,000 people with disabilities who were gassed in Nazi institutions, became its recognizable symbol. *California Network* members appeared regularly at legislative hearings and, in fact, at any policy hearing, any meeting, and any place in which the subject was addressed. Members held demonstrations; they also met with legislators and their aides to educate them about the issue.

The *California Network* wrote position papers, and members were quoted in newspapers and appeared in the editorial pages. The *California Network* formed a coalition called CARES with other like-minded advocacy and services groups, including Protection and Advocacy, Inc., California Association of Social Rehabilitative Agencies, and California Association of Mental Health Patients Rights Agencies. Eventually, through the efforts of the *California Network* and CARES, most of the mental health community opposed the IOC bill. Although working in a coalition, the *California Network* carried the torch in this fight against the expansion of forced treatment in California.

In 2002, after a four-year fight, IOC did become law in California. However, because of the efforts of the *California Network* and CARES and sympathetic lawmakers, the IOC law was watered down and filled with "voluntary programs" criteria that it would be difficult to implement in any county adhering to the law.

### ***Regional Self-Help Projects***

In the years since the *California Network's* reorganization, each region annually has chosen a self-help project. Many of these projects have been highly innovative.

- The Northern region developed a manual on a Buddy Program and conducted trainings on establishing a Buddy Program throughout the rural region. This was a program to partner those clients being released from a locked facility (hospital, 15-day hold, jails, etc.) with a peer in order to assist in re-connecting with the community.
- The Bay Area region created a Possessions Advanced Directive form, to make provisions for people's possessions, housing, cats and dogs, cars, and payment of bills when he/she is unexpectedly incarcerated or hospitalized.
- The Bay Area also produced a Peer Counseling video, in English and Spanish, and is currently, through client focus groups, developing the clients' perspective on stigma and discrimination.
- The South region educated providers about seclusion and restraints through a panel of clients who had experienced seclusion and restraints. Members of this panel became the presenters in many of the informational and legislative hearings on seclusion and restraints at the state capitol.
- The Far South region developed a client training of law enforcement that was honored by a statewide mental health organization.

The Peer Training Project (PTP) was a three-year program, funded by SAMHSA, which focused on trainings in client advocacy, emerging client leadership, learning to be effective members on policy-making bodies, and local organizing. Developed from a past Regional Project, the "What Do You Want?" Workshops became part of the PTP and were done in every geographic region of the state at least twice annually.

In all of its activities, the *California Network* has tried to strike a balance between its self-help/support arm and its public policy/advocacy arm, believing that both are equally important.



## OHIO ADVOCATES FOR MENTAL HEALTH



### *Developing a Directory of Local Self-Help Groups*

The Ohio Advocates for Mental Health (OAMH) conducted a survey to identify as many self-help/peer support groups as possible to determine their organizational structures, management, funding, and service arrays, and to learn about their technical assistance and training needs. From the survey, a directory was produced to link those seeking self-help services with nearby groups. More importantly, the groups surveyed all expressed an interest in greater networking among groups. This resulted in the formation of the Ohio Advocates Affiliated Self-Help Network that continues to share information and to meet regularly.

*OAMH* has developed a training program for the peer support/self-help groups covering community networking, advocacy, grant writing, marketing, public relations, and other issues that the groups have expressed an interest in sharing. The training sessions also serve as an opportunity for information sharing among group leaders. The individual groups are each locally organized and funded, and are only affiliated with *OAMH* and the Self-Help Network to the extent they choose to participate, ensuring that they remain autonomous. The number of peer support/self-help groups in Ohio has grown from seven in 1990 to more than seventy currently.

### *Technical Assistance to Local Groups*

Many of the local grassroots groups in Ohio, like those elsewhere, begin with a lot of enthusiasm, but often lack knowledge about the practical steps of running and sustaining an organization. *OAMH* provides technical assistance to groups all over the state, with a focus on such necessary matters as developing mission and vision statements, writing bylaws, becoming incorporated, building and sustaining a board of directors, and grant writing. This assistance ranges from simply meeting with groups to explore their long-range goals, to lending encouragement when their goals are to remain small and volunteer based, to providing more detailed and specific technical assistance when requested and needed.

*OAMH provides technical assistance to groups all over the state.*

An example is the role confusion that has occurred in several long-running groups when the members of the Board of Trustees are supervising a paid director. Those same Trustees may be serving as peer supporters/volunteers on other days by helping with groups and/or activities. They may also be using peer support themselves. *OAMH* has helped these groups to clarify the different roles that participants may have at different times.

Some groups face problems when they grow substantially in numbers of participants and had increases in funding. As a result of this growth, some have difficulty keeping up with the business management side of operating a peer support/self-help group. Unlike professional agencies, which have sufficient funding to staff various administrative functions, peer support self-help groups often have one paid staff position, which may not even be full time. Thus, there is often a conflict when sorting out priorities between supporting people and completing required paperwork. *OAMH* has provided training and leadership in assisting these groups to reassess priorities and to grow in ways that ensure both administrative and service needs are met.

### ***Statewide Cross-Disability Coalition Building***

*OAMH* has found it necessary to go outside the “mental health world” in its coalition-building. The Coalition of Healthy Communities, an existing mental health coalition that includes provider groups, parent groups, and local mental health boards, is not particularly friendly to *OAMH*’s mission and goals. Instead, *OAMH* joined a broad based cross-disability network, the Disability Policy Coalition (DPC), whose membership includes independent living centers and groups representing people who are blind, deaf, mobility impaired, or have developmental disabilities, cerebral palsy, or head injuries.

*OAMH has found it necessary to go outside the “mental health world” in its coalition-building.*

What the members of DPC have in common is that they are composed primarily of people with various disabilities, rather than professionals, service providers, and family members. The Disability Policy Coalition advocates on matters of common interest such as Medicaid reform, voter rights, and funding for programs that support people with disabilities. *OAMH* is also a member of the Ohio Olmstead Task Force (OOTF), which has been designated as the advisory committee to the Governor on development and implementation of Ohio’s Olmstead Plan. These coalitions are successful because the constituent groups all want the same things: to help people with disabilities be more independent and to lead productive, fulfilling lives.

A major issue for OOTF has been the disparate funding priorities that promote institutional living arrangements (nursing homes, ICFMR facilities) and discourage independent community living. The Disability Policy Coalition and the Olmstead Task Force have been very successful in educating people with disabilities about state budget issues, impacting the priorities in the Governor’s budget proposals, advocating with the Ohio Commission to Reform Medicaid, promoting home and community-based waivers to move people from nursing homes back into the community, and ensuring that citizens with disabilities are registered to vote and have an opportunity to do so.

DPC and OOTF have organized several state conferences for people with disabilities focusing on employment, voting rights, Medicaid buy-in, legislative advocacy, and other broad issues. For two consecutive biennial budget periods, these coalitions

organized more than 200 people with disabilities to attend budget briefings, and provided information, fact sheets, and mentors to assist people in visiting their state representative and state senator to advocate on budget and policy issues of concern.

## ON OUR OWN OF MARYLAND, INC.



### ***The Anti-Stigma Project***

This project was formed in 1993 in collaboration with the Maryland Mental Hygiene Administration, because *On Our Own of Maryland* recognized that consumer/survivors had a unique role to play in combating stigma. Unlike other mental health groups, consumers *themselves* experience stigma; it is not just an abstract concept.

In addition, *On Our Own of Maryland* recognized that much of the stigma was coming from within the mental health system itself—something that is usually not acknowledged by other mental health organizations. The mission of The Anti-Stigma Project is to fight stigma by raising consciousness, facilitating ongoing dialogues, searching for creative solutions, and educating all participants within or connected to the mental health community.

A workgroup of about thirty people was established, which included not only *On Our Own of Maryland* members, but also family members, representatives of state government, and others. This group has continued in existence and has produced a training video, “*Stigma... In Our Work... In Our Lives*,” funded by a grant from the Center for Mental Health Services.

In March of 2001, in partnership with the Substance Abuse and Mental Health Services Administration, Center for Mental Health Services, the Anti-Stigma Project hosted the first National Mental Health Symposium on Discrimination and Stigma in Baltimore, Maryland. The United States Surgeon General was one of the keynote speakers.

The Anti-Stigma Project has developed a number of workshops, which have been presented to consumers, providers, and administrators across the country as well as overseas. Approximately fifty workshops are presented annually.

### ***Main Street Housing***

The lack of integrated housing options for people in the mental health system is one of the largest obstacles to recovery. It is hard for someone in the process of recovery to feel like a “regular person” when he or she is living in a group home, halfway house, supervised apartment, or any kind of housing that is run by the mental health system. Rules are set by others, and freedom of choice is frequently limited, whether it is in the selection of roommates or the duration of one’s stay. Other people do not have to live

this way, and the goal of the Main Street Housing program is to make sure that mental health consumers have an opportunity to live in the same kinds of housing that people without psychiatric disabilities do.

In 2000, *On Our Own of Maryland* established Main Street Housing as a subsidiary housing development corporation, with its own Board of Directors, consisting of up to fifteen people, the majority of them consumers. The goal is to buy houses and lease them to people with psychiatric disabilities to serve as long-term housing. Unlike many housing programs, there are no requirements that people be in treatment, only that they fulfill the normal expectations of tenancy. Main Street Housing is just what it says it is: an organization committed to the idea that persons with psychiatric disabilities do not have to be hidden away on the back streets, that they have the ability and right to live on "Main Street."

*The lack of integrated housing options for people in the mental health system is one of the largest obstacles to recovery. It is hard for someone in the process of recovery to feel like a "regular person" when he or she is living in a group home.*

Main Street Housing now owns six houses: two in Hagerstown, two in Columbia, and two new properties in Harford County. In Hagerstown, the houses are duplexes (two units each); two of these units are rented to women with children, which is significant because most housing programs for people with psychiatric disabilities are for single adults only. A married couple occupies another unit, both with mental health histories. In Columbia, the buildings are three-bedroom townhouses, each of which currently houses three people (each with his or her own bedroom). The Harford County units are in the process of being rehabbed. Main Street Housing currently has plans to expand into several more counties; the goal is to double the number of units over the next two years.

Funding comes from a bond program run by the Department of Health and Mental Hygiene, which makes funds available to groups serving people with a variety of disabilities. The Maryland Department of Housing and Community Development, a mainstream housing agency not specifically designed for people with disabilities, has provided other funding for these projects. At present Main Street Housing is staffed by an Executive Director and a Housing Development Coordinator.

People who rent housing from Main Street Housing live normal lives: they go to school; they work; they come home at the end of the day. There is no limit on how long people can stay, but as they become more established in the community, some are moving out to “regular” housing.

Main Street Housing has established a tenant council to give tenants a voice in operating the organization. This unique independent “Housing Only” management organization contradicts the assumption of many mental health administrators and many members of the general public that people who have received mental health services need to be supervised and would not be able to manage in settings where they make their own decisions.

*People who rent housing from Main Street Housing live normal lives: they go to school; they work; they come home at the end of the day.*

### ***Olmstead Peer Support Project***

In July 1999, the Supreme Court issued the *Olmstead v. L. C.* decision. The case was filed by two women who were living in a psychiatric institution in Georgia, even though their doctors said they could live in the community. The Supreme Court decided that the Americans with Disabilities Act (ADA), which required states to administer their services, programs, and activities “in the most integrated setting appropriate to the needs of qualified individuals with disabilities,” meant that Georgia was violating the rights of these women. The *Olmstead* decision was an important victory for people with disabilities, who are often placed in institutions against their will even if they are capable of living independently. According to the Supreme Court, this is a form of discrimination and segregation that is barred by the ADA.

In practice, the *Olmstead* decision has not meant that everyone who wants to leave an institution can immediately do so; there are still a number of procedural difficulties. However, it has led to what is called an “*Olmstead* planning process” in each state to look at how the goals of the decision can be achieved. *On Our Own of Maryland’s* *Olmstead* Peer Support Project was established with a grant from the Maryland Department of Mental Hygiene in 2002. Three peer-support specialists were hired, who work part-time in three state institutions. They meet with consumers, both one-on-one and in groups, to help them understand their options in the community and provide them with important resources for the transition back to community life.

## VERMONT PSYCHIATRIC SURVIVORS



### ***Publication of Counterpoint***

The newspaper *Counterpoint* has been published quarterly for nearly two decades and has a circulation of about 7,000 readers, mostly within Vermont. It includes news about developments and issues in the mental health system statewide, information about local support groups, as well as artwork, poetry, and fiction by mental health consumers.

There is one paid staff position, an editor who works with an editorial board. Partial funding for *Counterpoint* is included in the *Vermont Psychiatric Survivors (VPS)* state grant, and additional financial support comes from subscriptions and donations. It is an important voice for consumers in the state and has also become recognized as one of the best sources of information about statewide and legislative issues in mental health.

### ***Safe Haven Program***

Safe Haven is a six-bed residence operated by *VPS*, with funding from the Department of Housing and Urban Development (HUD), serving people who are homeless and have psychiatric diagnoses. Unlike most programs for this group of people, there are no requirements that residents participate in mental health treatment. Instead, the intention is to provide a comfortable place for people to live, so they can make their own decisions about what kind of help and support they want. People living in the house get support from their peers and information about recovery.

*Unlike most programs for this group of people, there are no requirements that residents participate in mental health treatment.*

Safe Haven is licensed as a therapeutic community residence, and has been very successful in providing community housing for people coming out of the state hospital who have been unsuccessful in other, more restrictive programs. The program has two full-time employees as well as a number of part-time positions, including a house manager and a number of peer mentors.

Safe Haven is not intended as permanent housing, but some people, who had been in the state hospital for many years and came into the program with few independent living skills, have stayed for a year and a half to two years. As people have left the program for more independent housing, many continue to come back to celebrate holidays and have become a supportive community.

*VPS* is hoping to expand the Safe Haven program to other parts of the state, so that more people have the opportunity to live in housing that allows them to make their own decisions, and to benefit from a program that emphasizes recovery.

### ***Recovery Education Training Program***

Every year a number of Recovery Education groups are offered at diverse locations across the state and draw participants from every region as well as from surrounding states. The Recovery Education Program is closely allied with the Wellness Recovery Education Program (WRAP), an approach for helping people think about and plan for their own recovery that was developed by Mary Ellen Copeland.

WRAP started in 1997, with a group of consumers holding a series of meetings to discuss what helped them deal with problems that arose in the areas of health, both physical and mental, substance abuse, family, and relationships. In WRAP, people receive assistance in writing their own wellness plans and in implementing them when they are facing crisis situations or other difficult points in their lives.

Those guiding the process are recovery educators who have completed the process themselves and who have received further training on group facilitation. This program has prepared more than seventy-five people to be recovery educators. The educators are paid for the trainings they conduct, and some have used this experience as a springboard to further employment. Funding comes from a combination of *VPS*'s state grant, a SAMHSA Consumer State Network grant, and donations.







### ***PART III***

## **WHAT WE'VE LEARNED: PRINCIPLES OF SUCCESS**

Although at one time there were statewide consumer organizations in a majority of the states, many of these organizations have not been able to sustain themselves. There are many problems that cause groups to fail, including a lack of ongoing funding, lack of support from state government and mental health authorities, and internal problems, including organizational structural problems and dissension within the group. While the four organizations in the Recovery Consortium are not the only successful statewide organizations, there are lessons that can be learned from each of them that can help other states avoid these common pitfalls and build and sustain their own statewide groups.

When Consortium representatives compared their histories and activities, it became clear they all had certain fundamentals in common. Some of these relate to underlying principles; all the groups recognized that they shared basic beliefs, including:

- The necessity for the group to be consumer controlled;
- The importance of maintaining a focus on recovery;
- The valuing and respecting of different viewpoints, making room for minority position, and for holding and honoring multiple truths at the same time;
- The recognition of the importance of cultural competence, valuing people of varying ethnicities, races, sexual orientations, and other differences;
- The maintenance of a balance between advocacy and support activities.

### **CONSUMER CONTROL**

Although some statewide organizations begin under the auspices of the state mental health authority or another mental health organization (e.g., a Mental Health Association or the Alliance for the Mentally Ill), it is essential for the group to assert the principle of consumer control. This means that a group must eventually become independent, with its own funding, board of directors, and not-for-profit status. Even before this point, a successful group will adhere to the basic disability rights principle of “nothing about us, without us,” and it will insist on consumer/survivors speaking for themselves and representing their own interests.

## RECOVERY FOCUS

Often, it is *only* mental health consumer/survivors who truly believe in the possibility that everyone with a mental illness can recover. Groups can have varying positions on issues, but without a deep belief in the reality of recovery for everyone, there is little to distinguish the group from other, more powerful and well-funded voices within the mental health community.

As the rhetoric of recovery becomes more widespread, it is essential that independent consumer organizations ensure that what is being promoted is *real* recovery and empowerment—that is, the opportunity for people to make their own decisions and control their own lives.

## VALUING DIFFERENT VIEWPOINTS

Internal dissension has torn many groups apart. It can be very difficult to recognize and respect the many opinions within a group about such highly contentious issues as the use of medication, the value of mental health service programs, forced treatment, the existence and causes of mental illness, and the legal rights of people with psychiatric labels, among many others. Each of the groups in the Consortium have faced points at which internal dissent became a major issue, yet each has managed not only to survive, but to grow stronger by devising ways of ensuring that minority voices are heard, and that areas of agreement can be found.

At times when dissension within the group became a major issue, groups have relied on techniques such as consensus building and compromise. It can be very difficult to give up on a point when some people feel strongly; but if the existence of the group is at stake, sometimes people are more willing to compromise. At other times, it is a matter of choosing the right words.

*At times when dissension within the group became a major issue, groups have relied on techniques such as consensus building and compromise.*

In California, for example, there were members of the *California Network* who would not agree to “ending” forced treatment, but were brought together around the need to “stop expansion of forced treatment.” It can be a matter of picking the right battle—with so many issues on which members of a group *can* agree, sometimes it takes a willingness to put more contentious issues on the “back burner.”

Another important consideration is paying attention to people’s feelings. As organizations specifically focused on people’s emotional needs, it is important to recognize that hurt feelings, or a sense of being left out or ignored, is something all groups need to work very hard to avoid. Long meetings at which everyone is able to have his or her say can be exhausting, but that is sometimes better than making faster decisions which leave some people with hurt feelings that can be divisive in the long run.

## CULTURAL COMPETENCE

As organizations, we are composed of people from many different backgrounds; diverse ethnic and racial groups, rural and urban areas, and of different sexual orientations. It is important for groups to recognize these differences and to ensure that all people feel welcome. Policies need to be developed that encourage people to express their differences in language and culture, and to recognize that there is no one right way of doing things. We need to recognize, as well, that some people are uncomfortable around differences with which they are unfamiliar. A successful organization needs to develop a way for people to expand their awareness and understanding of those different from themselves.

Our organizations have not been completely successful at these efforts. We need to expand our efforts to translate materials into languages that are representative of people living in our areas. Some people from racial, ethnic, or sexual groups continue to feel uncomfortable in groups in which they are always in the minority. But paying attention to cultural differences and cultural competence pays off in the long run. Our organizations are stronger and more effective when they include *everyone* who has been in the psychiatric system.

## BALANCING ADVOCACY AND SUPPORT ACTIVITIES

Some people join consumer organizations because they are primarily interested in changing the mental health system, while others have self-help and mutual support as their primary focus. Successful groups have recognized that *both* of these functions are important. Although at times one or the other may, of necessity, take more of the group's time and attention, there is always a need to ensure that both thrive. Both are energizing, empowering, and often integral elements of individual recovery.

*Some people join consumer organizations because they are primarily interested in changing the mental health system, while others have self-help and mutual support as their primary focus.*

In addition to the principles outlined above, successful groups have also devised organizational structures that enable them to be both efficient and democratic. They have made sure that the members, board members, and staff work together toward common goals, and that roles are well defined and understood. Successful groups have developed good record keeping, so that accounting is accurate and money is spent in accordance with grant specifications and laws. They have participated in local and statewide coalitions to strengthen their voice and to advance their goals.

Groups often face a difficult period when a key leader leaves. Making the transition to new leadership is an important milestone for any group, and nurturing new and

emerging leaders is an essential activity of a successful organization. Each of the Consortium members has attempted to deal with this issue. In Vermont, for example, when the first executive director left, his mentoring insured that someone “from the ranks” was hired for the position. This person had held several jobs in the organization and was encouraged to think of herself as someone who could take on increasing levels of responsibility. California has worked to build a broad base of leadership development and empowerment training throughout its network so that there are individuals ready to step up to the plate when leadership positions open up.

One challenge is the low levels of funding even the most successful groups receive. It is very common for funding agencies to assume that mental health consumers will work as volunteers or at very low salary levels.

*Leadership development and ensuring a living wage for work in this area are significant issues that challenge current leaders, and affect our ability to nurture the next generation of consumer leaders.*

While the mental health field in general does not have high salaries, the executive directors of consumer organizations almost always receive salaries far below those who run other mental health organizations, even though they have the same skills and are doing a job that is equally difficult. Leadership development and ensuring a living wage for work in this area are significant issues that challenge current leaders, and affect our ability to nurture the next generation of consumer leaders.

Some of the groups in the Consortium have found it helpful to solicit funding from outside the mental health system. For example, *On Our Own of Maryland* gets community development money to operate Main Street Housing. When funding is not linked directly to the mental health system, it is easier for the group to take positions that may be in opposition to the system. *On Our Own of Maryland* learned this principle very early, when they took part in a lawsuit against the Department of Mental Hygiene, which threatened to revoke their funding. But since they had developed allies in other agencies of state government, this threat was unsuccessful, and they were able to show that they could both be forceful advocates *and* receive government funding.

Many of the groups in the Consortium also obtain funding from foundations. Writing grant proposals can be difficult and time consuming, but diversifying sources of funding is essential for long-term stability of a group.

## SUMMARY OF PRINCIPLES OF SUCCESS

Developing and sustaining a successful statewide organization takes strong leadership, processes which are inclusive and respectful, adequate funding, and, above all, a clear vision of the importance of speaking for ourselves and building structures that allow people to live more satisfying lives. The four organizations of the Recovery Consortium have maintained their success and their longevity by incorporating these essential elements into their day-to-day operations.

As people who have experienced the psychiatric system, and then have experienced recovery, we have much to teach our peers who also want and deserve the opportunity to recover. We have much to teach the mental health system, which is often stuck in the same old ways of providing services and seeing people who have been diagnosed with mental illness as helpless and needing to be guided and controlled. We have much to teach legislators, communities, and opinion leaders about our strengths and capabilities.

We have seen how strong statewide organizations can have a meaningful impact on public policy making. We have seen how obstacles and challenges can be transformed by a group into opportunities for growth and change. At a time when the mental health system is being called upon to re-think its programs and assumptions, it is more important than ever that our voices be heard, and that the principle of “nothing about us, without us” prevails.





## ***PART IV***

# **AMPLIFYING OUR VOICES: STEPS FOR CREATING A STATEWIDE MENTAL HEALTH CONSUMER ORGANIZATION**

## **WHY CREATE A STATEWIDE CONSUMER ORGANIZATION?**

The desire to create a statewide consumer organization always stems from an attempt to fill some kind of need. The primary drive for the creation of a statewide consumer organization (SCO) is generally the need to have a united consumer/survivor voice in addressing policy and rights issues and in ensuring a recovery focus within the system. A statewide consumer organization affords an effective means of uniting the consumer voice and taking a stand on foundational principles.

It is important for consumers to take the lead in the systemic transformation process in their states and be recognized individually and collectively as the authority in their own lives. A statewide presence creates a vehicle for concentrated consumer involvement and a way for consumers to secure their own future more effectively.

*“It is important to have more voices at the table and to make sure it is our table.”*

*Mike Finkle of On Our Own of Maryland*

The work of addressing these issues can be fragmented and ineffective when there is not a unified consumer statewide presence. It is too easy for policy makers to ignore individuals or groups that are in conflict internally about their message or goals. It is much more difficult to ignore the power of many voices when they ring out clearly, consistently, and in concert with each other.

Further, individuals can easily become disenchanted or “burned out” when they try to work alone. It is hard work to transform a service system and success is rarely immediate. As a group, we can help each other to lift flagging spirits when needed, as well as allow space for people to get more or less involved at various times as needed or desired.

A frequent experience of those who have mental health problems is a sense of isolation. It is important to know others have a shared experience and similar concerns. Often, a prevalent force driving the creation of an SCO is the need to exchange information about advocacy issues, health concerns, housing, employment, benefits, recovery, and various other issues. The SCO provides for the exchange of

information statewide and results in being an important source of connection and support.

Involvement in a statewide network of consumers provides a vehicle for personal empowerment as people grow beyond the limited image of their diagnosis and assumptions about what is achievable in life.

*“This is really about civil rights. The real issue is informed choice, which is a foundational principle. We believe given adequate information everyone is capable of making a choice for themselves.”*

*Doug DeVoe of Ohio Advocates for Mental Health*

It is clear that a key element in developing and maintaining a successful statewide network is the ability to form and nurture relationships. Having personal mental health issues can often disrupt one’s ability to feel connected and to form relationships. A consumer organization creates an opportunity to form meaningful and productive connections on all levels, both among peers and in the wider world.

As individuals grow in personal empowerment and take on the various tasks required to start and grow a successful SCO, leadership skills are developed. Finally, and perhaps most importantly, a statewide consumer organization affords the opportunity to dispel stigma by demonstrating the reality of recovery and how effectively we can speak for ourselves.

*“We hear all the time how lives are changed by being part of a larger group and see how both the group and the individuals are made stronger.”*

*Sally Zinman of the California Network of Mental Health Clients*

In summary, the needs driving the creation of a statewide consumer organization include:

- Creating a united consumer voice to shape policy and address rights issues
- Establishing vehicles and forums for exchanging information
- Providing opportunities for personal empowerment
- Developing leadership skills
- Building relationships
- Finding connection and support
- Creating opportunities to model recovery.

The experience of Recovery Consortium members and other statewide organizations reveals some common patterns and steps in the process of creating a successful statewide network. Drawing from this shared expertise, this chapter presents a set of steps and practical activities that will help those who are establishing a statewide consumer organization.



## WHERE DO WE BEGIN?

The process in creating an SCO has three basic steps, but there are many activities within each step. First, you get people and ideas together and begin writing down what your vision of a statewide consumer organization would look like. Second, you put in place all the “bones” of an organization—its structure, what it does, the processes for getting things done, and so forth. And third, you grow and expand. These three basic steps are listed below and each of these stages will be discussed in more depth in the following sections.

1. **Visioning**
2. **Developing Organizational Structure**
3. **Expanding the Network**

Although the stages are presented here sequentially, it is important to understand that creating an SCO is not usually a linear process, meaning each stage does not necessarily follow the other as we’ve outlined here. Each of these activities is important, ongoing, and often intertwined. To have a successful start-up you must do all three. To keep your group alive and motivated and to sustain your SCO over time, you must review and revisit them regularly.

The skills and passions of your members, and the opportunities and resources available to you, will determine how you proceed through these stages and activities. Some of the challenges include where to focus your attention at any point in time, how you meet developmental needs or challenges, and the ways your group will share the tasks of organizing, developing, and expanding your SCO.

## STEP 1: VISIONING

Visioning is the process of painting a word picture of what your SCO will look like: what it will do, what values and principles give it shape and meaning, who will be involved, how it will be structured, how things will get done, and essentially, what success will look like.

It is good to develop a formal business plan. It helps to articulate who you are and where you’re going. The components of

*Visioning is the process of painting a word picture of what your SCO will look like: what it will do, what values and principles give it shape and meaning.*

a business plan are similar to those needed for requesting funding. There are some excellent resources on the Internet and from the Small Business Administration. Your group may not need the same detail as a corporate business plan, but it is good to have a basic plan in writing. Funders in particular typically need formal descriptions and

plans, budgets, and other documents before they are willing to consider providing resources. To promote or advertise your organization, it is also necessary to have things written in ways that make it appealing to others.

### ***Establishing a Strong Recovery Focus***

Since mental health system transformation is a primary objective of SCOs, it is important that all statewide networking activities are based on the fundamentals of recovery. It is helpful for at least a few people in the group to become familiar with the writings, research, and policy documents about recovery in mental health to understand current thinking about recovery, as well as what political pressures and opportunities may be available for transforming the system toward more recovery oriented services.

While you may be promoting the SCO throughout the state and trying to get many people involved, it is also important to

*Consistently using recovery-based language helps to demonstrate the reality of recovery.*

encourage participation of people who can show recovery in action. Telling our stories is an important aspect of showing others that people can and do recover. Remember, we are the evidence!

Consistently using recovery-based language helps to demonstrate the reality of recovery—and by contrast, the reality that many services are entrenched in non-recovery oriented practices and attitudes. Recovery language includes using the term “recovery” often and with meaning, telling our stories, sharing our experiences honestly, talking about “people” rather than disorders or diagnosis, focusing on hope and ability not on difficulties or pathology, and remembering that there are many “pathways” for achieving goals whether the changes desired are personal, programmatic, or systemic.

### ***Developing a Planning Group***

It is necessary to have a core group of passionate and dedicated individuals to work together to get a statewide network off the ground. This can be called a “planning team” or “steering committee.”

*SCOs are typically started by a small group of people with a vision and drive.*

There are several reasons to have a planning team. SCOs are often started by a small group of people with a vision and drive and the SCO takes root and grows from their efforts. Even if you have a large and willing group of interested persons to start with,

it is difficult to do some of the administrative tasks of creating an SCO en masse. Planning teams, however, should never work in isolation from the larger group, but instead always work in an open and collaborative way.

There should be enough people on the planning team to be able to divide tasks, but not so many that the decision-making process gets bogged down. Some networks have

started with a core group of three to five people. Others have had six to eight team members, and some have found sixteen to eighteen people to be a workable number. More than that can be cumbersome. In selecting planning team members, people should first and foremost be passionate about and committed to the idea of a statewide network, as they will be developing, holding, and sharing the vision. Further, it is important to involve individuals with demonstrated leadership ability and strong skills. Recruit people who stand out as competent leaders. Perhaps they have provided key advocacy, or legislative action. Perhaps they lead an already existing organization or have demonstrated an ability to bring people together. It is important that they have strong communication skills, good listening skills, be able to maintain consistent work, an ability to put personal agendas aside, and be able to work with others toward a common goal.

A successful SCO is comprised of individuals with varied skills, experience, and interests to take on the numerous tasks involved in developing, maintaining, and growing the SCO. In addition, it is a good idea for group members to be regionally and culturally representative. This is as important for small states such as Vermont that need, for example, both the northern and southern parts of the state represented, as it is for states like California which are very large geographically and include many ethnic, linguistic, and cultural groups.

One of the questions you will need to grapple with is whether the planning team for the statewide consumer organization should be 100 percent consumer/survivors or not. What if your state DMH

*One of the questions you will need to grapple with is whether the planning team for the statewide consumer organization should be 100 percent consumer/survivors or not.*

wants to have a liaison to the group in order to help it get established? What if that person is the consumer affairs director? What if a local family group is the spearhead trying to get something going in your state? What if a service provider organization is willing to promote the group, give it space, or serve as a fiscal agent until it becomes fully independent? Should someone from that organization be on a planning group? There are no right or wrong answers to these questions. Just know that these are some issues that you will need to decide early on in your process.

The Massachusetts planning team was an all-consumer team. The representative from DMH was the Consumer Affairs Office Director. They also convened a stakeholder committee of community leaders, funders, providers, and family members in a parallel process whose task was to look at how to support the work of the planning team. The Consumer Affairs Office Director was on both committees.

### ***Determining Group Leadership***

Often there is someone with a strong personality driving the statewide organizing process. This person is usually a dynamic leader who can articulate a vision and unite

others in a common cause. This person's strong communication and team-building skills act as a catalyst in the early days of the organization's development. It is important, however, that the work of the statewide network not rest on the shoulders or personality of one person, or even a few. It is imperative for long-term success that the leadership works in the service of the collective voice. A statewide network must be dedicated to its grassroots identity, which means that those in leadership positions are representing the collective wisdom and desires, rather than their own personal agendas.

*Part of good leadership is to help others feel empowered and to nurture new leaders.*

Part of good leadership is to help others feel empowered and to nurture new leaders. The group leader should be someone who can share responsibility, encourage group identity and ownership, and promote leadership in others.

There are many examples of networks that fizzled after a dynamic leader moved on and there was no one willing or able to take on the leadership. "Growing" new leaders through empowerment, support, and mentorship is crucial for long-term success of the SCO. Some people do not realize that they have leadership potential, but a good leader will always look for this potential in others and then help them to discover it for themselves by learning new things, taking some risks and gaining confidence.

### ***Planning Team Meetings***

Establish a structure of how and where the planning team will meet and for how long. Often it takes one to two years to build a viable statewide network. Some networks meet regionally at designated intervals while having local work groups. Others meet in a central location at agreed upon times. Decide whether your meetings will be in the form of regional evening forums, one-day work sessions, weekend retreats, or some combination of these. It is helpful to close one meeting by scheduling the next so everyone knows what to expect.

Meeting spaces can be found in many places. Sometimes the state Department of Mental Health or a local mental health agency will make conference rooms available for consumer/survivor network planning. Educational facilities like colleges, universities, and even local school systems have public meeting places that may be used. Hospitals, churches/temples, community recreation centers, and libraries often have space for meetings.

Sometimes space is available through supportive groups such as mental health associations, other advocacy groups, established consumer-run centers or drop-in programs, or other human service organizations such as veteran centers, community action, or housing organizations. Even private homes can be used. Usually meeting spaces can be found at no cost, but it is important to respect your host and honor the rules or policies of the venue. Always check ahead about things like smoking and food policies of your host, hours, keys, who is responsible for clean up, and so forth.

Transportation is a common issue for people, so it is useful to design a meeting structure that makes it as easy as possible for people to attend. This could mean organizing car pools, scheduling meetings at a place or time when people may already be congregating such as a conference or other event, and applying for planning grants that will provide some funds for transportation or childcare expenses. Sometimes teleconferences or speaker-phones can be helpful to link with people who want to attend but simply cannot get there. Some states or educational facilities have interactive television capacity that may be available for these activities. This allows people to come to designated local sites and be able to see and talk with each other around the state through special television connections.

An effective use of time is to bring the planning team together for periodic retreat weekends, while holding regional work groups in between. This approach allows for some social time as well as the intensive and time-consuming work of hammering out the vision, values, action agendas, work plans, and other aspects of developing the SCO.

*Transportation is a common issue for people, so it is useful to design a meeting structure that makes it as easy as possible for people to attend.*

### ***Conducting Meetings***

The productive use of meeting time is an important consideration. Unfocused or non-productive meetings are often a “turn-off” for participants who want to feel their contribution of time and effort is meaningful and valued. There should be clarity about the purpose of the meeting. Making an agenda either in advance of the meeting or as the first activity can help keep things on track by providing both structure and clarity.

*Unfocused or non-productive meetings are often a “turn-off” for participants who want to feel their contribution of time and effort is meaningful and valued.*

As a group, decide together about the rules and guidelines for participation. These guidelines are agreements about how you will communicate and treat each other respectfully. When there are guidelines

that the group has designed together and agreed upon, there is a higher level of buy-in and the entire group has ownership of the meeting. The meeting will run more smoothly and be more productive when all participants know and agree on the format.

The responsibility of following the agreed upon guidelines is shared by the entire group, so if someone talks beyond his time or becomes disrespectful, one person does not shoulder the responsibility for setting limits and no one feels singled out. The following are some common guidelines for successful meetings.



## Guidelines for a Successful Meeting

1. Always have a meeting agenda.
2. Send the agenda to all participants a few days prior to the meeting.
3. Always begin meetings on time.
4. At the beginning of the meeting, ask for additional agenda items or changes to the existing agenda items.
5. Set an agreed upon time allowed for each agenda item. Some items may require ten minutes while others may be allotted an hour. Stick to your agreement for allotted time for each item.
6. Make a decision whether to table unfinished items until next meeting, have them go to subcommittee or work group, have someone agree to do follow-up, draft a proposal and email the group between meetings, or some other plan for follow through on unfinished items.
7. Agree upfront on guidelines for participation. Guidelines may include things such as:
  - One person speaks at a time.
  - Each person has an agreed upon length of time to speak.
  - All communication is respectful.
  - Each person has an opportunity to participate.
  - People return from “fresh air” breaks in a timely manor to not hold up meeting
  - “Respect for all” builds a sense of responsibility and personal and group accountability
  - Other agreements the group feels are important.

### ***Ensuring Inclusiveness***

As people join the network, it will be important for them to become involved in some area of passion and interest, some way they can feel their unique skills have a place and purpose. Some people like the public “out front” roles while others prefer to be behind the scenes. Sometimes, simply being present at a meeting or event is important and the best contribution someone can make. There needs to be a place for everyone!

In our interviews, the overwhelming majority of organizations said that inclusiveness, especially in decision making, was the number one priority for start-up activities and for achieving longevity of the network. The value of inclusiveness was also found to be a common ingredient of the consumer-run services and programs in the federal COSP research by Jean Campbell.<sup>16</sup> There must be a process that includes everyone. The job of the leadership is to ensure this process is in place and working.

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<sup>16</sup> For more information see, Clay, S (Ed.), 2005. *On Our Own Together: Peer Programs for People with Mental Illness*. Nashville, TN: Vanderbilt University.

This is no small task, since within the ranks of consumer/survivors is an extremely wide range of experience, values, beliefs, needs, and desires. Most consumer/ survivor organizations develop a structure and a process where all who wish to express opinions

*It is vital to have a forum where people feel safe enough to discuss ideas and be heard.*

have the opportunity. All agree that it is vital to have a forum where people feel safe enough to discuss their ideas and be heard, as well as to be open and respectful while listening and learning from others.

Because there is such a range of experience and belief among consumer/survivors, it is important to place a priority on finding common ground and, if necessary, agreeing to disagree. Some organizations use a model of framing all discussions in “I” statements, such as, “When I was in the hospital, I experienced this...” “What is important to me is...”

Successful statewide consumer organizations always try to include divergent opinions and recognize that all people need to feel heard and respected. In order for an organization not to seem elitist, there must be a way to solicit input regularly from consumer/survivors across the state.

Go where the people are. Some SCOs send their team leader and/or members into rural and remote areas of the state to meet with people, to talk about issues, to get their input and to encourage their further involvement. Some planning teams hold local or regional forums to give people a chance to have a voice in the process.

Some networks have found that holding a statewide conference is a good way to bring people together to share ideas and gather input. SCOs also use statewide conferences to develop position papers on important issues and/or to establish action priorities for the organization.

*Some SCOs use statewide conferences to develop position papers on important issues and/or to establish action priorities for the organization.*

Another way to determine grassroots priorities is to use surveys. There are many ways to use surveys to gather input, including surveying people attending a conference and mailing surveys out to a wider selection of people from all cultural groups around the state.

Some states have the challenge of a large geographic area and a small population. In those states particularly, it can be difficult just to find out where consumers/ survivors are located. It can be invaluable to have the help and support of existing organizations that have contact with consumer/survivors, such as provider agencies, mental health centers, support groups, drop-in centers, clubhouses, hospitals, NAMI (National Alliance on Mental Illness), local Protection and Advocacy organizations, disability law centers, community bulletin boards, and so on.



While many people do not have access to computers, an increasing number do have them at home or through programs, libraries, and worksites. Using a website posting, listserv, or other online technology can supplement other outreach strategies.

Confidentiality is an important issue for consumer/survivors—and for mental health agencies, it is a legal issue as well. Agencies will not provide you with lists of their clientele so that you can contact them or send them a survey. However, agencies may be willing to distribute information for you and encourage people who are interested to get in touch with you. When you leave information for agencies to distribute, it is good idea to get permission ahead of time and make sure your contact information is on your materials.

*Gathering input from constituents will be an ongoing task.*

Begin a list or database with the contact information of everyone who gets in touch with you and you will begin to develop one of an SCO's most important resources—people!

Gathering input from constituents will be an ongoing task of the organization that goes beyond the visioning stage of a new SCO. In order to have longevity, the SCO must convey to consumers in all areas of the state that they are needed and can make a meaningful contribution to the process of transforming the system. Thus, there needs to be a regular and systematic way for people to voice their ideas about how the organization should prioritize its focus and activities, and continued involvement in decision-making.

### ***Finding Focus and Purpose***

It is important to decide early on what the focus of the statewide network will be. Will the purpose of your SCO be to influence policy, take legislative action, or provide peer support? An important thing to consider is how to use the collective voice to represent the diverse perspectives, interests, and priorities of the members.

The primary reason to have a statewide network of consumer/survivors is to establish a unified voice.

*The primary reason to have a statewide network of consumer/survivors is to establish a unified voice.*

However, people also need to feel involved in something personally meaningful. Many of these organizations have decided upon focus areas, with each of the areas having a mission, goals and objectives, and activities. The following list of focus areas might be useful to new groups:

- Public Policy
- Self Help and Support
- Organizational Infrastructure
- Stigma and Discrimination
- Diversity-Minority Issues.



Be realistic in the number of focus areas the group can manage. You may wish to prioritize them not just in terms of importance or immediacy of action required, but also according to your network's ability to work on them. Perhaps your SCO will identify ten focus areas that are important, but the group will work on only one or two while developing your membership. This is OK! The others become goals to work toward later.

Rather than spread your energy, effort, and resources too thin, it is usually better to focus on one or two priority areas, concentrate all your effort on those and experience some success early on. Even limited success on your focus areas will be the best advertisement you can have for your group. People want to get involved in successful endeavors. Sometimes the focus areas take on a life of their own and become a separate entity, such as the Main Street Housing Program in Maryland or Safe Haven in Vermont.

### ***Creating Mission and Value Statements***

A mission statement outlines the fundamental purpose or “mission” of your SCO. Values statements list and define the core guiding principles that are sacred or uncontested within your group.

Mission and value statements form a kind of “glue” for the organization that provides cohesion for the group and often form an area of consensus—something we all agree upon.

*Mission and value statements form a kind of “glue” for the organization.*

Mission and value statements also serve as a checkpoint to help with decision-making. For example, “Are we staying true to our mission if we take on that project?” “Does that policy we just wrote reflect our value about inclusion?”

### ***Writing a Mission Statement***

A mission statement articulates the essential nature, the values and the work of an organization. An effective mission statement must resonate with the people working within the organization as well as with the different constituencies the organization hopes to affect. It must express the organization's purpose in such a way that inspires involvement, commitment, and loyalty.

It is important that mission statements are written by the entire group, not by one or two individuals and then given to the membership for approval. The process of writing the statement is usually as powerful as the final product. Have the members of the planning team each contribute ideas as to wording that is inclusive and comprehensive in describing the mission of the statewide network. One or two people

*A mission statement should be:*

*Visionary and Broad*

*Realistic*

*Practical and Workable*

*Motivational*

*Easily Understood*

*Short and Concise*

may take on forming these ideas into one statement, but they should not try to tackle it without this broader input.

The challenge in devising a mission statement is to state what your group is about in a comprehensive yet concise way. The mission statement does not need to include everything your group plans to do, just the overall purpose of the organization.

Use your identified focus areas to begin the work of creating a mission statement. Ask yourself, “What is common about the things we want to achieve? What do they say about us, about who we are, what we do, what we stand for, and what we are trying to achieve?”

Your mission statement should be no more than three to four sentences. Each word is important. Begin by simply brainstorming a list of words that express your values and purpose, what you hope to accomplish, and how your organization will make a difference in your state.

Highlight the words that evoke a strong “YES!” as a way of expressing what your organization is about. Begin tying the words together with strong action verbs into a list of phrases. See how you can combine words and phrases to eliminate redundancies. Pick out the strongest phrases and condense into three or four sentences.

The mission statement does not need to express everything about your organization.

*Your mission statement is not the vehicle to preach or convince. It is the vehicle to invite and inspire.*

This is not the vehicle to preach or convince; it is the vehicle to invite and inspire. It should be concise enough that anyone in your organization can readily repeat it. As you work to condense the statement, you will be generating lots of powerful ideas and be tapping into deeply held passions.

Have a way to capture the ideas, concepts, and phrases that are discarded as part of the mission statement but fall into value statements, focus areas, or things to address in a strategic planning process.

To summarize, the mission statement should:

- Express purpose in a way that inspires support and ongoing commitment;
- Motivate those connected to the organization;
- Be easy to grasp and understand;
- Use proactive verbs;
- Be free of jargon;
- Be short enough that anyone connected with the organization can readily repeat it.

Appendix B has a number of examples of mission statements from other statewide organizations that may be helpful as you think about yours. These examples show a variety of ways to approach mission statements. While you may see some commonalities, each statement also reflects what is unique about the organization.

Resources found on the Internet can be helpful in writing mission statements. For example, the following sites have good material on this topic:

- [www.tgci.com/magazine/98fall/mission.asp](http://www.tgci.com/magazine/98fall/mission.asp)
- [www.bplans.com/dp/missionstatement.cfm](http://www.bplans.com/dp/missionstatement.cfm)

Women's business centers and the Small Business Association in your area often have resources and may even offer help for developing mission statements and other organizational development questions.

### ***Developing Values Statements***

Creating a list of value statements that are important to the organization is a priority for SCOs because they help us think clearly about what values we honor and cherish. Often we don't take the time to name or share our ideas about some of these things—we just take them for granted. However, when we sit down and try to come up with a list everyone agrees upon, along with definitions and examples of how we live these values as an organization, we are encouraged to identify and discuss the philosophy and principles that shape us as individuals, as a group and as an SCO. In addition, we are helped to come to agreement about what is important to us as a group, not just as individuals.

Some examples of values that SCOs have felt important are recovery, freedom of choice, respect, honesty, empowerment, diversity, and community.

*Some examples of values that SCOs have felt important are recovery, freedom of choice, respect, honesty, empowerment, diversity, and community.*

There are a number of reasons why it is important to take the time to create a values statement:

- Values statements can be a very useful to help build cohesion and accountability within the SCO, as well as to shape the identity of the organization from the outside – how others view you. Are you an organization that lives your values?
- The values statement can also be used to guide personal and organizational decisions, for example, “Does this activity fall in line with our values?” This is what it means to be “values-driven.” Your values guide *all* your decisions.
- Value statements can be used in times of interpersonal conflict as a means of aligning people's actions to a set of guiding principles. For example, “If respect for diversity is one of our values as a group, how can we deal with this conflict in a different way?” “How can we listen to differing opinions with respect?”

- A mission statement and a statement of guiding principles or values are often a helpful tool for securing funding and support. Potential funding sources often look at them to learn more about your organization, its purpose, and values.

Some organizations use their values statements to help shape their missions, while others look to see what values are embedded in their mission statements. Some organizations' mission statements include a list of values that are important to the organization. Other organizations choose to create a separate document. Start with what makes the most sense for your SCO.

If you are starting a new organization, drafting an initial value statement may be one of the jobs of the planning committee. However, it is a good idea to review and reevaluate the organization's mission and value statements periodically so that they stay fresh and current as the organization grows and changes. You may find beliefs and values change over time or are influenced by new perspectives or ideas different people bring into the organization. Mission and value statements should be fluid enough to change as the SCO matures, while at the same time providing a sense of continuity and purpose.

## STEP 2: DEVELOPING ORGANIZATIONAL STRUCTURE

### *Establishing an Infrastructure*

Any successful organization needs a strong business infrastructure. A solid organizational infrastructure helps us to get things done by defining various roles and processes, establishing authority and decision-making procedures, establishing processes and tools that help us to be accountable to each other as well as our funding sources and our community. It also determines our legal designation as a group, business, not-for-profit corporation, and so forth.

Find people who have strong, savvy business management and development skills within the consumer community to develop and maintain the ongoing business framework of the organization.

The organization will need to develop a business plan, incorporate as a 501(c)3 not-for-profit organization, establish a budget and a system for keeping financial records, answer phone calls, develop informational materials, monitor activities for adherence to grant guidelines, write reports for funding agencies, and develop new funding resources. Also needed are office space, desks, telephone system, computers and software, and office supplies.

Seek funding for the establishment of the organizational infrastructure before taking on projects or agreeing to deliverables (specific "products" such as a report, survey, etc.). Be clear about priorities. Agreeing on too many deliverables at the same time the infrastructure

*Don't stretch your group too thin! Be mindful and realistic about the energy and resources of the organization.*

is being built can be a setup for failure. Don't stretch your group too thin! Be mindful and realistic about the energy and resources of the organization, right from the onset.

### ***Incorporating as a 501(c)3 Organization***

In order to have tax-exempt status and be eligible for tax-deductible funding, your organization must have not-for-profit status. In short, a 501(c)3 organization is a type of nonprofit organization classified by the federal Internal Revenue Service (IRS) as either a "public charity" or a "private foundation." An organization becomes classified as a not-for-profit organization by submitting a 501(c)3 application to the IRS.

*An organization becomes classified as a not-for-profit organization by submitting a 501(c)3 application to the Internal Revenue Service (IRS).*

Educational, charitable, religious, and a variety of other humanitarian groups and private foundations are eligible to apply for this designation.

Being "non-profit" doesn't mean you cannot make money. It does mean that you are exempt from state and federal taxes, and that any "profit" earned by your organization is returned to the organization, not to shareholders or stockholders.

It can be daunting to prepare for submitting a 501(c)3 application. It can take a lot of time and effort by many people. Recruit people who are familiar with the 501(c)3 application process, and have the ability to write a business plan and to write grants. Local colleges and universities often have business centers that provide free assistance with these tasks. The Small Business Administration also provides free assistance. Your group may also seek technical assistance from other statewide organizations that have gone through this process.

There are a number of excellent sources of information and assistance about the process of applying for not-for-profit status and what an organization must do to begin the application process. The National Consumer Supporter Technical Assistance Center (NCSTAC) of the National Mental Health Association has an excellent online publication about "*How to Establish a 501(c)3*" that is available at no charge.<sup>17</sup> The National Mental Health Consumer Self-Help Clearinghouse also has a number of relevant and helpful materials.<sup>18</sup>

### ***Securing Funding by Seeking Allies***

Who are your potential supporters and allies in your state? Who is sympathetic to your cause?

Most statewide networks start with federal or state funding, and most, if not all, have started with the help of

*Most statewide networks start with federal or state funding, and... with the help of allies.*

<sup>17</sup> National Consumer Supporter Technical Assistance Center (NCSTAC), National Mental Health Association, 2001 N. Beauregard Street, 12th Floor ; Alexandria, Virginia 22311; (800) 969-6642. Website: <http://www.ncstac.org>

<sup>18</sup> National Mental Health Consumers Self-Help Clearinghouse, 1211 Chestnut Street, Philadelphia, PA 19107; (800) 553-4539; Website: [www.mhselfhelp.org](http://www.mhselfhelp.org)

allies in the funding and legislative bodies of their state. *On Our Own of Maryland* was started with the help of a sympathetic administrator in the Maryland Mental Hygiene Administration. In California, the Citizens' Advisory Council to the state Department of Mental Health supported the need for a united statewide consumer organization. Ohio had the strong support of the state's Director of Mental Health who had an advocacy background and supported the principle of consumer organizing. The Division of Mental Health in Vermont has been very supportive of the statewide consumer efforts.

The secret to funding is developing relationships. Discover who controls the funding in your state. Identify who has the power to give you what you need and establish relationships with those people. Often there is a synergistic way of finding like-minded people in power positions, based on mutual need.

Look for strong, like-minded, non-consumer allies. Then select people who already have relationships with these potential allies to be part of the planning and development process. Find areas where your organization and your potential allies share common ground or have mutual needs.

*Find areas where your organization and your potential allies share common ground or have mutual needs.*

Establish relationships with your state community support program and/or state mental health authority. Many have received statewide networking grants from Center for Mental Health Services (CMHS) of the Substance Abuse and Mental Health Services Administration (SAMHSA) of the federal Department of Health and Human Services (DHHS). Some receive federal block grant money through their states. The National Mental Health Association has also provided some grants to consumer-run organizations. Private foundations can also be a source. For example, *VPS* in Vermont has received funds from the Van Amerigen Foundation.

Draw on the skills and contacts of those consumers in your state who have been doing legislative advocacy and have relationships with state legislators. Recruit those who serve on policy councils within the provider and funding agencies.

*As you are growing relationships, also gather support letters to keep in your files.*

It is a good idea to get letters of support from your allies. These letters can be a vital part of a grant proposal to show the positive impact a consumer organization has. Letters of support lend credibility and invite participation of others. Everyone wants to be part of an organization that seems to play a vital

role in the community and has the support of influential community leaders. As you are growing relationships, also gather support letters to keep in your files. You will find many ways to use quotes from them.



### ***Developing Ongoing Collaboration with Stakeholders and Allies***

A statewide consumer organization provides a valuable resource for many people concerned with policy and services related to mental health. Address mental health issues and statewide networking as a community issue. Create or join community coalitions and partnerships with organizations and institutions that can support and promote the values of a statewide consumer organization.

Think outside the box. Think beyond the mental health system. Who has a stake in a united, empowered, responsible consumer presence? Who are your allies?

*Think outside the box. Think beyond the mental health system.*

*Develop relationships with individuals, groups, agencies, and organizations that share the need for a united consumer presence.*

Think about all the organizations and areas of community life that are affected by mental health issues. Develop relationships with individuals, groups, agencies, and organizations that share the need for a united consumer presence and would lend energy and support to the project. These might include interfaith organizations, housing authorities, sympathetic legislators, business leaders, cross-disability groups, family members, provider agencies, and funding organizations.

One idea is to invite supporters to form a stakeholder committee whose purpose is to expand support and find renewable funding sources for the network.

### ***Establishing Basic Governance and Decision Making Policies***

Most SCOs have strong values around shared decision-making and minimal organizational hierarchy. However, it is important to have some established, agreed-upon way for making decisions and getting things done. Generally, important

*It is important to have some established, agreed upon way for making decisions and getting things done.*

decisions should be made either by democratic vote or by consensus. In both cases there is a process of inviting input from constituents.

The planning team, which often becomes the board of directors when a newly form SCO becomes incorporated as a not-for-profit organization, either makes a final decision by majority vote or by a consensus process. Although the consensus process takes much longer, consumers often prefer this option since many have had experience in the mental health system where they felt they did not have a voice.

In the consensus process, all members must agree with the decision. One member has the power to stop the process and be heard if he or she has a strong objection to the decision. After voicing the opposition, another vote is taken. Often people change their minds after hearing a strong argument for or against a decision. If there is not consensus in the follow-up vote, the item is tabled for further discussion and vote at a later time. People discover where they can find compromise and where they hold steadfast opinions.

*Crafting consensus policy decisions helps everyone feel included in the process, and allows for a minority opinion to have as much weight as the majority viewpoint.*

The consensus process is surprising in that it often inspires people to find common ground and find ways to navigate conflict so that everyone can agree with a final decision. Rather than table an important topic, people discover ways to find

language on which all can agree. The benefit of consensus is that all members feel involved and included. Crafting consensus policy decisions helps everyone feel included in the process, and allows for a minority opinion to have as much weight as the majority viewpoint.

One example of how this works is in California, where all final decisions about advocacy initiatives are decided by consensus. If there is not total consensus, the *Network* will not take an action or voice an opinion, although they encourage individuals to have an independent voice by taking action on those issues they personally feel strongly about.

Sally Zinman advises, “*Crafting issues to preserve the unity of the statewide organization is vitally important.*” Divisiveness can destroy an organization. Consider what is most important – being “right” or having your way, or the unity and survivability of the organization itself. People rarely agree 100 percent on anything, but try to find the areas of common agreement and work from there. Your organization will be stronger for your efforts.

Groups sometimes decide to have some combination of democratic majority-rule vote and consensus process. They identify which topics require the longer consensus process and which can or need to be decided through a quicker majority vote.

*What matters most is that the decision-making process is clearly defined, understood, and agreed upon by all members and that everyone feels heard and part of the process.*

It doesn’t matter what form of decision-making process is used. What matters most is that the decision-making process is clearly defined, understood, and agreed upon by all members and that everyone feels heard and part of the process.

### ***Creating a Communication System***

Create a way to have an information loop for communication to flow both to and from the members of the statewide organization. People need to be kept informed and up to

*People need to be kept informed and up to date on issues, what is happening around the state, and where and how their involvement is needed.*

date on issues, what is happening around the state, and where and how their involvement is needed. Without regular communication, people tend to feel marginalized, lose interest, and drift away from the network.



Some SCOs have found a monthly newsletter to be a valuable way to report on happenings around the state, inform constituents of upcoming events or legislative action, highlight opportunities to influence policy, list area support groups, and invite feedback on important issues. Other communication tools are bulletin boards, chat rooms, fax machines, direct mail, telephone trees, and regional contact people.

Begin by compiling a database of members and supporters with rigorous standards of confidentiality and anonymity in safeguarding this information. You may want to have email information for those people who have computer access so you can create a listserv and send the same information out to a large group of people at one time.

Be sure to have a policy of never selling or making public your membership list and let your members know of this policy. If the network shares its list with other organizations for disseminating information or invitations to events, there should be an opt-out option that members can select if they don't want their information shared. Rather than give the mailing list to another, allied organization, some groups send out the mailing themselves to insure confidentiality.

### STEP 3: EXPANDING THE NETWORK

You can think about the stages of growing an SCO the same way you think about growing a garden. In the "Visioning" stage you are looking at seed catalogs and talking to others about what kind of garden to grow and what it will look like.

In the "Establishing Organizational Structure" stage you are digging and fertilizing the soil, giving the garden shape, planting the seeds, waiting for them to take root, and coddling the seedlings through bad weather.

The third stage of "Expanding the Network" is when you do whatever is needed for the young seedlings to grow, mature, blossom, expand, and even set seed. It is the ongoing work of nurturance, troubleshooting, and creating something that is sustainable over time.

There are two important aspects of the "Expanding the Network" stage. The first is solidifying and expanding membership and gaining credibility and influence. The second is creating sustainability over time so that the SCO is not dependent on a few individuals or a single funding source.

#### ***Organizing Membership***

It can be helpful to have a way to formalize membership in the SCO. This can give people a feeling of inclusion, commitment to and ownership of the network. It also has benefits for the SCO.

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Formal membership allows the SCO to know how many people are involved in the network and provides a way for gathering and updating contact and mailing list information. Knowing these numbers can be powerful when applying for funding or establishing credibility as a voice for a constituency.

Knowing how many people are members of the organization and who they are has additional benefits for the SCO. For example, it:

- Provides the SCO with a defined pool of people who can be approached and counted on to get involved in various initiatives or activities.
- Allows the SCO to reach out to individuals who do not continue their membership, to find out why, and encourage renewed involvement.
- Gives the SCO a way of tracking its growth over time, for example, from a small group with twenty members to a large one with over 500 members. If the SCO receives a grant for network development, these numbers are important measures of success and accountability for the funder.

Most statewide organizations establish an annual membership fee. These fees are typically minimal and do not constitute a large portion of the operating budget of the SCO, but they are a source of income. Every little bit helps!

*Most statewide organizations establish an annual membership fee.*

Here is a typical membership fee structure:

- Low-income membership (those on entitlement programs): \$2 per year
- Consumer membership: \$10 per year
- Non-consumer membership: \$25 per year
- Affiliate membership (supporting individuals and organizations): \$100 per year

Some groups create a sliding fee scale based on income.

Think about what people get as members that non-members may not, such as newsletters, invitations to conferences, a membership card, reduced fees on publications and so forth. Because of the power of group purchasing, sometimes an SCO can arrange for special privileges or discounts for its members.

Decide whether to provide membership cards. Some SCOs provide membership cards and some do not. Some members like having a token signifying their membership; others do not care. If a membership fee is charged, it may be beneficial to have cards with the expiration date of membership. If your organization decides not to charge a membership fee, membership cards may be an unnecessary or undesired administrative task and expense.

### ***Forming Coalitions***

Some statewide organizations are structured as a coalition of existing groups, some are an organization of individuals, and still others are a combination of the two.

One way to create a statewide organization is to form coalitions with existing local or regional consumer/survivor groups. The statewide organization can serve as the hub of a wheel, linking a variety of groups into a network.

*The statewide organization can serve as the hub of a wheel, linking a variety of groups into a network.*

For example, in Ohio, seventy self-help groups united in a statewide consumer organization to form a peer support network. The local or regional groups still exist, but they find their voice and influence amplified as a coalition, especially on statewide policy issues. They also have the opportunity to pool their efforts and resources for initiatives or activities that benefit all the groups such as public education campaigns or creating self-help training materials.

Consumers in Alaska have developed an innovative way of forming a statewide coalition of consumer-run peer-support organizations. After watching fellow organizations compete for the existing grant funding being awarded to peer-run programs in Alaska, where some programs got funded and some did not, they began to explore the notion that perhaps there was a way for *every* program to be funded.

An invitation went out for all consumer-run organizations in Alaska to come together. Some of these organizations had longstanding rivalries and very different values and perspectives. Rather than trying to form a unified group where consensus was found, they used a different approach. They acknowledged the common ground of consumer-run values, that the fact that they were all peer-run programs was the key. They decided that *all* the programs were good programs, run by good people and they would focus on how to support each other rather than compete with one another.

They began meeting three times a year, obtaining a small grant to provide transportation to the meetings, and rotating host organizations and location. They call themselves The Alaska Consumer Consortium, a fellowship of peer-support organizations. They spend time getting to know each other's history, mission, flavor, and dreams. There is total transparency in which each organization shares its budget and funding sources.

As they share their proposed work-plan and funding needs, they work toward finding a way for each organization to be funded. This is done by sometimes offering compromise. They become excited by each other's plans. One organization may offer to do only half their plan and submit for half the funding amount originally sought, so that another organization's program can be funded.

When they are done, they submit a coordinated funding proposal, making the process much less random and competitive. The organization providing the funding in Alaska is very pleased by this cooperation and opportunity to fund every program requesting support. Alaska Consumer Consortium found an effective way of uniting and supporting each other without losing each organization's individual autonomy and mission. They stand on the four common denominators that they share:

1. We're all from Alaska
2. We're all consumers
3. We're all seeking funding
4. We're all working toward recovery

And their uniting values are principles of non-competition and respect for each other as individuals and as organizations. They began four years ago with 5 organizations, and now the consortium is comprised of 22 organizations.

### ***Establishing Ongoing Grassroots Involvement***

In all statewide consumer organizations it is good to have a plan for ongoing grassroots involvement. A consumer network will only be viable as long as the statewide grassroots membership

*A consumer network will only be viable as long as the statewide grassroots membership feels that the network is effectively voicing their concerns and acting in their interests.*

feels that the network is effectively voicing their concerns and acting in their interests. This will be achieved if the grassroots membership feels included in setting priorities, making decisions, and has a valued role as part of a group.

It is helpful to have a structure for regular outreach and mechanisms for gathering input, as well as ways to share the tasks that need to be done in order to fulfill the mission of the SCO. As noted previously, yearly statewide consumer conferences, as well as regional meetings, forums, and leadership retreats, are parts of the ongoing structure of many organizations.

*Ohio Advocates for Mental Health* has an eighteen-member, geographically representative Board of Directors. Every other month the Board comes together for a Friday night dinner and formal board meeting. Their subcommittees then meet and work on Saturday. The subcommittees focus on external policy, media relations, and internal policy.

*On Our Own of Maryland* is a coalition of twenty consumer-run organizations with a Board of Directors largely comprised of members from different regions of the state. As in Ohio, Maryland's network benefits from working together on statewide policy issues and sharing concerns from their local region resulting in problem-solving strategies.

In California, which is divided into five geographic regions, the *California Network of Mental Health Clients* places a priority on developing structures that allow for equal representation on all policy issues. All work groups include one representative from each region. The statewide network holds a yearly conference where they draft public policy for the year. Each region also holds regional conferences and two-day meetings throughout the year.

*Vermont Psychiatric Survivors* hold board meetings every other month, quarterly leadership meetings called the Recovery Workgroup, and an annual conference.

## ***Creating Safety***

Every person needs a safe harbor in which to express oneself. This is especially important in the consumer/survivor movement where personal safety can be a key issue. There are often widely divergent needs, perspectives, and opinions that may be

expressed in many different ways. Some people have had experiences in which they did not feel emotionally or physically safe to express themselves or felt threatened by others' self-expressions.

*It is important to create a safe environment where all are invited to express what is important to them, but where people also share responsibility to keep the environment safe for others to do the same.*

It is important to create a safe environment where all are invited to express what is important to them, yet where people also share responsibility to keep the environment safe for others to do the same.

There are several things that can be done to help create a safe environment. Some of these include paying attention to the physical space, making sure meetings are facilitated in a skilled manner, negotiating and enforcing guidelines for respectful participation, and addressing confidentiality.

## ***Physical Space***

The first aspect to consider in creating safety is the physical space. It is important to create an inviting atmosphere that helps people feel safe to express their opinions and their desires. Equally important is for individuals to be able to leave easily if they feel unsafe or threatened in any way.

*The physical environment plays an important role in creating safety.*

When setting up the room, check for the following:

- No barrier between those conducting the meeting and participants.
- Each person can see all of the other participants.
- The space is conducive to conversation.
- The room setup creates a level playing field.
- Exits are clearly marked and unlocked at all times.
- There are places outside the meeting room where people can go to calm or reclaim a sense of safety, if needed.

### ***Skilled Facilitation***

Conducting a gathering where all participants feel safe enough to authentically express themselves requires skilled facilitation. There are a number of important facilitation tasks. For example:

- Keep the group on task and on time according to the agreed upon agenda.
- Encourage and support quiet individuals to speak.
- Keep the more talkative persons from dominating.
- Restate what a person may be having difficulty saying.
- Listening “between the lines” to what is really being said.
- Reading the tone of the group to know if a break is needed or the pace needs to be changed.
- Mediating conflict that arises.

*Facilitation does not have to fall to one person. It is the responsibility of the group itself to take on these jobs as needed to ensure safety for everyone.*

These facilitation tasks do not necessarily have to fall to one person only. It is the responsibility of the group itself to take on these jobs as needed to ensure safety for everyone.

Some qualities of an ideal facilitator are:

- Accepting of one’s own feelings
- Comfortable in front of a group
- Able to elicit participation from the group
- Attentive to group dynamics, acknowledging and addressing conflict
- Recognizes and invites participation from less talkative people
- Has strategies to discourage gently someone who dominates conversation, pushes his or her personal agenda, or strays off topic
- Has a high tolerance level and is not shocked easily
- Accepting and inviting, yet firm when needed
- Holds to the agenda without getting sidetracked
- Demonstrates and holds the group to a principle of respect.

### ***Guidelines for Participation***

Guidelines for participation were discussed briefly as an element of organizational development, but they are also a key element in creating safety for participants. By addressing the topic of respectful communication as a group, individuals have an opportunity to talk about meeting etiquette, honoring diversity, and shared responsibility.

When the ground rules are collaboratively decided, then there is better “buy-in” and more mutual responsibility for enforcing them. Remember, it is the group’s responsibility to enforce its ground rules, not just the facilitator’s responsibility.

Many groups find it useful to establish an agreed-upon length of time both for individual sharing and for agenda items. For example, no one person can talk for more than five minutes unless the group gives him or her explicit permission to carry on. Some newly forming groups have had success using a “talking stick” which is an object that gets passed around and only the person holding it can talk. If a group establishes time rules, it must be also diligent in enforcing them or else they become meaningless.

Following is an example of some “Guidelines for Participation.”



### **Guidelines for Respectful Communication**

We each bring rich and diverse experiences, information, attitudes, and beliefs. We must each take personal responsibility for what information we share, for the manner in which all information is shared, and for helping to create an environment that is safe, respectful and mutually supportive as well as productive. Below are our guidelines for respectful communication:

- We share a mutual and active responsibility to create a safe and healthy setting in which each of us can share ideas, opinions, and feelings.
- We assume there will be diversity of experiences and opinions and will not assume that others share our point of view.
- We will listen to each other attentively and non-judgmentally. This means only one of us can talk at a time.
- Instead of shooting down others’ ideas, we will be non-critical and we will try to build upon them.
- We will respect each other’s confidentiality and not share personal information about each other without permission and will not talk about someone when they are not present.
- We will hold each other accountable to respectful communication by challenging disrespectful and negative or inaccurate assumptions when we hear them from each other.
- We will take personal responsibility for making it clear we feel we are “not being heard” instead of just “checking out” or complaining after the meeting.
- We expect conflict and see it as an opportunity for growth and creativity. We are committed to working through conflict by negotiating compromise in order to craft solutions that will work for everyone.
- We will hold unconditional high regard for everyone.
- We will have fun in the process!



## ***Confidentiality***

In order for most people to feel safe they need to know that when they share personal information it will be held in confidence. Therefore, it is a good idea to begin each meeting going over your agreements and ask participants to agree to a principle of confidentiality. That means that each person agrees to respect each other by honoring each person's right to share his or her own experience and not have it repeated outside the meeting.

## ***Conflict***

Most people feel that conflict is a sign that things have gone wrong. On the contrary, conflict is an inherent part of advocacy and change work. We cannot do without it, for without conflict there is no change.

*Most people feel that conflict is a sign that things have gone wrong. On the contrary, conflict is an inherent part of advocacy and change work....*

*Without conflict there is no change.*

Think about how boring everything would be if we all simply agreed with each other. There would be no challenge and nothing to force us to think in new ways or about different things. We would not learn much about each other or ourselves. And things would stay just the way they are. We deal with conflict every day. The trick is to deal with conflict so that it yields positive and growth-producing consequences rather than becoming a force that hurts, destroys, alienates, or interferes with achieving our goals. It is unrealistic to think people will come together from different backgrounds and experiences, having various needs, belief systems and desires, and not have significant differences.

Conflict is a natural way of bringing what is important to the surface. It is important to understand that conflict is good. It means your group is alive and vital and that people care. When people are complacent and simply go along with what others want, there is no conflict. When people are invested or empowered they are willing to struggle for what they care about.

*Linda Corey of Vermont Psychiatric Survivors has another perspective on conflict.*

*"Conflict is an opportunity to train people in self-advocacy skills. Here is an opportunity to find your voice, express what is important to you, teach others about your point of view, and to learn from others what is important to them. People appreciate honesty. Model that and encourage others to speak honestly."*

That having been said, conflict is uncomfortable and scary for many of us. We have had many life lessons about conflict in our homes and families, at our jobs, and in our communities. These have shaped our comfort level with conflict and taught us various ways to handle it. Some of us just try to avoid it; some of us jump right in and do whatever it takes to get our own way. Some of us go "underground" and try to get our way in less direct ways; yet others take on the role of peacemaker.



When organizations experience conflict it is very similar to conflict in our personal lives. We have to remember that how we handle organizational conflict can mean life or death for the SCO. It is not uncommon for internal conflict to be the reason that promising networks do not fulfill their potential or even fall apart. It is important to handle conflict skillfully so it can be a constructive part of the organization's growth.

There are some excellent resources for learning how to manage conflict in an organization.<sup>19</sup> Some of the key factors for successful conflict resolution are your attitude and approach to it, interpersonal communication skills, problem solving, and knowing when to get an outside mediator to help. Following are some tips and hints for dealing with conflict when it arises.



### Some Tips for Managing Conflict

- Celebrate conflict. Remind those involved that this conflict is evidence that everyone cares deeply about the issues at hand.
- Conflict is an opportunity for all parties to discover something about themselves.
- Deal with conflict immediately. Do not wait to address it next month. Do not think it will just go away.
- Use conflict to demonstrate there can be constructive outcomes when conflict is used as a means of expressing oneself. Being heard and listening to others with mutual respect and intention to learn from one another is productive, even if a resolution is not found.
- Enter conflict with a win/win attitude.
- Foster conversation. Encourage the parties involved to talk with each other. Conflict can become divisive if conflicting individuals talk to others rather than each other.
- Encourage people to use "I" statements and avoid attacking language.
- Clarify the Issue. Separate the content from the process. Clarify, "This is indeed what is being said". "This is what the concern is." Separate issues from personalities.
- Use guiding principles and values to guide interaction.
- Remind conflicting parties of their commitment to the greater project.
- Determine the needs of each party.
- Give each person an opportunity to speak without interruption about what the issue is for him or her, what he or she feels and wants.
- Look for common ground and creative solutions. Affirm that there is a way to find a solution to this conflict and a willingness to seek a way for each conflicting party to find what will work for him or her.
- Consider an outside mediator with skill in conflict resolution.
- Consider organizational training in conflict resolution.
- Find a model of communication that can be used in conflict. Non-Violent Communication is one effective model.

Adapted from: Rosenberg, Marshal B. (2005). *We Can Work It Out: Resolving Conflict Peacefully and Powerfully*; Chicago, IL: Puddle Dancers Press, [www.cnvc.org](http://www.cnvc.org)

<sup>19</sup> Your local library will have a number of books on conflict resolution, negotiation, and mediation. You may also consider *Managing Workplace Conflict: A skills training workbook for mental health consumers and supervisors*, by S. Shore & L. Curtis, available from the National Research and Training Center on Psychiatric Disability, University of Illinois at Chicago. [www.psych.uic.edu/MHSRP](http://www.psych.uic.edu/MHSRP)

## SUSTAINABILITY: KEEPING THE ORGANIZATION ALIVE

We have touched previously on many aspects needed to keep the organization alive and thriving. It is important to cover some of those things again with a particular focus on sustainability. Three key elements of sustainability are vision, leadership, and funding.

### *Vision*

When an organization is started, the planning team takes care to gather input to articulate and implement a vision. Many organizations make the mistake of relying on that original vision long after they have been established. For the organization to be a thriving, sustainable entity, it must change and grow in response to various elements both within and outside the organization.

A tension between sustainability and organizational growth may occur within the SCO. Some members may resist change, wanting to remain true to the original vision. Others may ask, “What are we sustaining? Is our organization still relevant to the issues of today?” A question to ask is, “Are we open to new ideas, opportunities, partnerships, and approaches?”

It is wise to engage in a new visioning process periodically, perhaps every three to five years. This would be the time to revisit your mission and value statements and your business plan. Evaluate what has been working well that you might want to expand on. Also, look at the areas of the organization’s focus that are weak or need adjusting or rethinking. Is your organization welcoming to new people and is it culturally diverse and open to differences? Have you identified new needs that you were unaware of at first? Have you made new allies or community contacts that open some new possibilities?

All projects generally unfold a little differently than the original plan. Visions look good on paper, but real life often has problems, issues, and roadblocks that you hadn’t considered. Along with problems, new opportunities and perspectives may emerge as well. A thriving organization is one that can reassess and change direction to avoid pitfalls or to take advantage of a new opportunity.

It is also important for the organization to stay current as social, political, and economic climates change. In the developmental stage, establish a plan for a future visioning process. In the initial five-year plan, you might build in a strategic planning process for assessment and future visioning.

### *Nurturing New Leaders*

To prevent burnout among leaders and the team and to create a viable statewide presence for the long term, the SCO must have a plan for ongoing leadership development. Some SCOs use CONTAC’s Leadership Academy, NEC’s Finding Our Voice Training, or other trainings that may be available.

Some SCOs use formal or informal mentoring programs to identify, educate, and support emerging or potential leaders. An organization is only sustainable if it reaches out to all diverse constituencies. It is important to include leaders that represent the cultural, ethnic, gender and geographic diversity of your state.

- FORMAL MENTORING involves structured training that may include pairing an emerging leader with an established consumer leader who would share the wisdom and experience gained over time. Some organizations of retired business persons, minority enterprise development programs, and women's business associations may offer formal mentoring at little or no cost.
- INFORMAL MENTORING is when an experienced leader is always observing people's passions and interests and perhaps he or she encourages someone to get involved. Then a few weeks later the leader may ask that person to help with some project or activity. As time goes on perhaps the experienced leader shows the new person how to do some new task and then might turn that task over to the new person. In time, as that person's confidence and skill level increases, she or he is taking on new tasks and more responsibility and, in a very subtle way, becomes an emerging leader.

*Whether you use formal or informal leadership development, it is a key element in the success and sustainability of your organization.*

Whether you use formal or informal leadership development, it is a key element in the success and sustainability of your organization. Not only does it keep the grassroots involvement alive, the increased skill level of individuals fosters empowerment and increases the overall impact of the organization. Also, when everything falls to one or two key people, the organization may fall apart if those people are not available for any reason.

### ***Funding***

Most SCOs began with state or federal grants. Many have CMHS (Center for Mental Health Services), SAMHSA grants. However, reliance on these grants as a major source of funding is not a sustainable approach for the long haul.

*"Is our funding mix so narrow that we will be out of business if it is reduced, or even cut? Do we want one funding source to have that much power over the life of our organization?"*

In nature, environments with a greater variety of plants in a specific area are more able to adapt and thrive during periods of drought and environmental stress. They are therefore more sustainable than those areas with fewer varieties. This is also true with organizations.

Some key questions to ask are, "Is our funding mix so narrow that we will be out of business if it is reduced, or even cut? Do we want one funding source to have that much power over the life of our organization?" Diversity in funding mix is a sustainability issue.

How do you achieve a diverse funding mix? Keep your funding radar on! Make yourself aware of funding sources in your state and community. Mental health issues are human issues that affect all areas of community life, yet most SCOs look for funding within the small “mental health world.” Make mental health a community issue in your state.

Who could you partner with—employers, faith-based organizations, art councils, foundations, influential families, housing authorities, urban leagues, civic organizations, faith-based social service agencies? Think outside the “mental health” box. Get creative. Who do you know? Who do your members know? Who would you like to know?

Invest in a fundraising and/or grant writing training.<sup>20</sup> Recruit someone with those talents into your organization. Look for in-kind donations (goods or services rather than money) from local businesses and organizations. Seek pro bono (free) help. Law firms, for example, often donate free legal assistance to not-for-profit groups. Look at developing income producing services such as training and consulting services. Charge even a minimal membership fee. Produce some products you can sell. (Remember when you sell a product you must collect sales tax within your state and send the tax collected to the appropriate authority.) Make this an exciting endeavor to discover how many diverse streams of funding you can develop.

### ***Nurturing Relationships and Partnerships***

The success of your statewide organization will depend greatly on the organization’s ability to develop and nurture relationships of all kinds. First and foremost is the relationship with consumer/survivors themselves – your grassroots constituency. Included in this manual are several necessary steps for creating a sense of involvement and input from the grassroots constituency. This is of utmost importance since there will be no statewide network without tending to relationships with consumers across the state.

Equally important is attending to relationships among the membership of the SCO, including at the level of the planning team or board of directors. There will always be challenges and tensions, such as the ongoing issues of authority and decision making processes, how fast to grow, whether to purchase a building or hire staff, people who want to take on too much control or power, board members with personal agendas, members who continually disrespect others or repeatedly break rules, disgruntled ex-members, what to do when a grant is reduced, and so forth. These tensions can only be effectively resolved by working through them in a mutually respectful and responsible way. Healthy organizations accept that these tensions will be there and

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<sup>20</sup> The National Consumer Supporter Technical Assistance Center has a “Guide to Proposal Writing” that is useful and straightforward. National Consumer Supporter Technical Assistance Center (NCSTAC), National Mental Health Association, 2001 N. Beauregard Street, 12th Floor ; Alexandria, Virginia 22311; (800) 969-6642. Website: <http://www.ncstac.org>

work to develop a culture within the organization that faces each challenge with understanding, honesty, and tenacity. Our strength lies in our relationships.

Relationships with stakeholders, allies, funding entities, and legislators are also essential to your success and longevity. Be sure to include them on your newsletter lists and ask their involvement in matters of concern. Continue regular meetings and always be on the lookout for additional allies.

*The success of your statewide organization will depend greatly on the organization's ability to develop and nurture relationships of all kinds.*

*Our strength lies in our relationships.*

Successful SCOs have discovered the importance of forming coalitions with groups that have a common interest. You may have disparate values or disagree with these groups on other issues, but on THIS issue your interests are best served by working together. So just do it and agree to disagree on the other things, at least for now. You may find there are unexpected benefits to be had simply by reaching out.

Finally, develop and nurture relationships with statewide consumer organizations in other states. None of us should have to reinvent the wheel in our efforts. Many states have accomplished what you are attempting. Many have faced similar challenges. Find out how they handled these difficulties. Seek their encouragement, support, and technical assistance. Get input and suggestions from many sources. Be willing to adapt others' ideas so they will work in your situation.

### ***Celebrating!!***

In our interviews, when asking about important ingredients for longevity and sustainability, we were told, "Don't forget to have parties!"

*We all need to take time to sit back and talk about what we have accomplished.*

Sometimes it is easy to see only what went wrong or what we were not able to accomplish. Stay focused on the positive and celebrate your successes. There is usually another opportunity to tackle the tougher things. It is important that we celebrate and appreciate our successes every step of the way. It is about

appreciating the journey and acknowledging what we have learned that will make us better and stronger.

We all need to take time to sit back and talk about what we have accomplished. Successes can be small as well as large. Perhaps you can include a "celebrations" section in your newsletter. Our grant application was successful. YES! We were able to preserve funding for consumer-run programs in this budget. YES! We have increased our membership by 25 percent over the past year. YES! One of our members wrote an influential article that was published in the paper; was asked to teach the

nursing students at the local college; published in a journal; had an art gallery opening. YES!

Celebrations are informal ways to build trust, respect, and meaningful relationships. They are opportunities to get to know other dimensions of people, and where we have shared experiences and interests besides our mental health histories. It is important to create times where people can interrelate in informal settings where people relax and enjoy each other.

Celebrate birthdays, holidays, non-holidays. Find ways to have fun. Include a dance or karaoke in your gatherings and conferences. Create possibilities for social gatherings as well as work-related times. These are often the places where we forge the relationships we need to be successful. An organization that is vitally engaged in relevant issues and activities will attract people and draw them into involvement.

### BECOMING THE TRANSFORMATION YOU WISH TO SEE

Transformation is about creating a new paradigm in mental health care. In the old model, people were given diagnoses that often carried expectations of lifelong care, broken dreams, and stigma. Instead of working with a person, it worked with a constellation of symptoms. The system treated symptoms, medicated symptoms, managed symptoms, committed symptoms. Somewhere in all of this the person disappeared, sadly accepting this bleak situation or not realizing there were alternatives.

After decades of consumer organizing, there have been significant gains. We are involved in a paradigm shift as the mental health system takes on the challenge and mandate of transforming to a more recovery-based caring system. We are at the table more often, sometimes even with an invitation. We are taking on roles as peer supporters and program administrators, demonstrating that there are other ways of helping individuals, ways that encourage and support persons to find their own pathways to health and wellness, to recovery.

We are creating the model for this transformation. We know what recovery looks like. We are living it. As we create more ways to be involved in policy making, in legislative action, in peer support, in community partnerships, and in shaping services, we must be the example of what we wish to see. That means we must be healthy. We must relate to each other with kindness and compassion. We must seek common ground. We must work with our adversaries without being adversarial. We must call ourselves and others to the highest ground. We must live our values.

### THE FUTURE: WHERE ARE WE GOING?

The pioneering work of the Recovery Consortium members and other consumer organizations has built a solid foundation upon which newly forming statewide consumer organizations can stand. These groups of passionate, talented, dedicated

individuals have made a real, lasting, and significant impact on mental health services and have improved the quality of life for themselves and others in their states.

As a result of decades of hard work, the opportunities for consumer involvement in shaping services and in changing the world in which we live are more expansive than ever before. We are witnessing the opening of new doors to consumer involvement in guiding mental health policy.

As a result of the New Freedom Commission, there is a mandate to have all mental health services be recovery focused and consumer driven. Seven states have recently been awarded a SAMHSA/CMHS *Mental Health Transformation State Incentive Grant* to transform their mental health service systems. Connecticut, Maryland, New Mexico, Ohio, Washington, Texas, and Oklahoma have been given the funding to assess current services and policies and to reshape policy, services, and training to align with the New Freedom Commission Report. We are the voices critical to this process of transformation. It cannot be done without us.

As you work to form your statewide organization, take some time to vision a future, just the way *you* would like it. Ask your constituency, “If you could create a mental health system just the way you would like it to be, what would that look like?”

As you create your statewide organizations, ask yourselves, “If we achieve everything we hope to accomplish, and we were looking back six years from now, what would be different?”

Don’t be afraid to dream and dream big. Do not focus on what the drawbacks are currently. Visioning involves freeing the mind beyond limitations.

Perhaps these are some things we could begin to bring into reality:

- A National Coalition of Statewide Consumer Organizations with every state having representation
- Additional consumer/survivor-run programs—local, regional and statewide—throughout the country
- Peer professionals in every state
- Recovery-focus as part of professional training in universities and hospitals (with each statewide organization creating a consulting service for this)
- Making services more accessible
- National program to end homelessness
- Consumer/survivors being viewed and valued by the system as the experts on recovery

You can add to this list. What does transformation look like to you? Visionary work is not about coming up against “what is”; it is about demonstrating another way. It is about showing and leading the way. It is about informing and inspiring others to

change their viewpoint. Begin to see yourselves as the visionaries, as the leaders in this transformation process. Let us create a future where people are not stigmatized because they are suffering, but instead find a system of support and sanctuary to help them reconnect with what is most essential.

You *ARE* the future – a voice of transformation. The work you do to create a statewide consumer organization is important in shaping the environment and experience for consumers in your state. As Kenny Loggins says, “*Let your rage be the fuel for your truth telling.*” Let that truth telling be the fuel for your action. Let that action create a better place for you as individuals and for your organizations.

May your work be inspired by the dedication of those individuals and groups such as the Recovery Consortium members, who have paved the way for the remarkable opportunities that await each one of us. May this manual guide and inspire you.



## APPENDIX A

### RESOURCES

#### GRANT WRITING AND/OR OPPORTUNITIES

<p>SAMSHA website for Faith Based and Community Initiatives Website: <a href="http://www.samhsa.gov/FBCI/fbc.asp">http://www.samhsa.gov/FBCI/fbc.asp</a></p>	<p>The SAMHSA web page for faith-based and community initiatives provides resource information for faith based and community initiatives including grant writing, technical assistance, publications and grant review opportunities.</p>
<p>Grants.gov Program Management Office 200 Independence Avenue, SW Hubert H. Humphrey Building, Room 739F Washington, DC 20201 Phone: 800-518-4726 Website: <a href="http://www.grants.gov">www.grants.gov</a></p>	<p>Grants.gov provides one-stop on-line resources for federal grants offered by the Department of Health and Human Services including SAMHSA. A free quarterly newsletter (<i>Succeed Newsletter</i>) is also available to receive the latest news, events, and updates about Grants.gov.</p>
<p>The Foundation Center 79 Fifth Avenue and 16<sup>th</sup> Street New York, NY 10003 Phone: 800-424-9836 or 212-620-4230 Website: <a href="http://www.foundationcenter.org">www.foundationcenter.org</a></p>	<p>The Foundation Center provides information about US Philanthropy and serves the general public. The Center provides research on trends in the field, training and education on the grant seeking process, provides access to information and other services to the public via the web.</p>
<p>The Grantsmanship Center P.O. Box 17220 Los Angeles, CA 90017 Phone: 213-482-9860 Website: <a href="http://www.tgci.com">www.tgci.com</a></p>	<p>The Grantsmanship Center offers training and low-cost publications to non-profit organizations across the country. A membership with the center entitles an organization to future training discounts, continued support in grant writing activities, and searchable databases for a nominal fee for various time periods.</p>
<p>Substance Abuse and Mental Health Services Administration Grant Home Page Website: <a href="http://www.samhsa.gov/grants06/default.aspx">www.samhsa.gov/grants06/default.aspx</a></p> <p>For mental health: P.O. Box 42557 Rockville, MD 20857 Phone: 800-789-2647 (English/En Español) TDD: 866-889-2647 Website: <a href="http://www.mentalhealth.samhsa.gov">www.mentalhealth.samhsa.gov</a></p> <p>For substance abuse treatment and prevention: P.O. Box 2345 Rockville, MD 20857 Phone 800-729-6686 (English/En Español) TDD: 800-487-4889 Website: <a href="http://www.ncadi.samhsa.gov">www.ncadi.samhsa.gov</a></p>	<p>The SAMHSA Grant Home Page provides information on new grant material and information for applicants on how to respond to SAMHSA Request For Applications (RFAs). Additional information is provided on workshops for grant writing training and technical assistance. Printed copies of an announcement upon request. You will need the RFA number to request printed copies of these items from the clearinghouses identified to the left.</p>

<p>White House Office on Faith-Based and Community Initiatives  Jim Towey, Director  The White House  Washington, DC 20502  Phone: 202-456-6708  Website: <a href="http://www.fbcj.gov">www.fbcj.gov</a></p>	<p>The White House Office on Faith-Based and Community Initiatives was created to strengthen and expand the role for faith based and community organizations in social services. The website also contains information on funding opportunities and conducting business with the federal government.</p>
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## NEWS AND UPDATES

<p>Consumer Affairs E-News  SAMHSA/Center for Mental Health Services  Consumer Affairs  1 Choke Cherry Road, Suite 6-1069  Rockville, MD 20857  Phone: 240-276-1330  Paolo del Vecchio, <i>Associate Director</i></p> <p>Website:  <a href="http://www.mentalhealth.samhsa.gov/consumersurvivor/">www.mentalhealth.samhsa.gov/consumersurvivor/</a></p>	<p>The Consumer Affairs E-news is the electronic newsletters sponsored by SAMHSA/Center for Mental Health Services Consumer Affairs. The electronic newsletter promotes the participation of consumer/survivors in all aspects of the mental health system and disseminates information about activities and resources to promote the goal. Visit the website to obtain more information and to access information about other activities.</p>
<p>FirstGov News</p> <p>Web access  Website: <a href="http://www.firstgov.gov">www.firstgov.gov</a></p>	<p>The FirstGov News is a component of the Federal Citizen Information Center. FirstGov News allows you to select from a number of newsletters you wish to receive electronic newsletters. Examples include news on business, social security, education and publications. Visit the website to select the updates you would like to receive. Use the website listed to the left; click on the Site Index then click on News to go to the portal for newsletter subscription requests.</p>
<p>New York Association of Psychiatric Rehabilitation Services (APRS)  1 Columbia Place, 2nd Floor  Albany, NY 12207  Phone: 518-436-0008  Website: <a href="http://www.nyaprs.org">www.nyaprs.org</a></p>	<p>The New York APRS provides an electronic email that disseminates up to date information on mental health systems at the national, state and local levels. Visit the website to sign up for the newsletter.</p>
<p>Outreach Partnership Program  Public Information and Communications  Branch, National Institutes of Mental Health  6001 Executive Boulevard, Room 8184, MSC  9663, Bethesda, MD 20892  Phone: 301-451-2803 or 866-615-6464  Español available  301-443-8413 (TTY) 866-415-8051 (TTY)  Email: <a href="mailto:nimhinfo@nih.gov">nimhinfo@nih.gov</a>  Website:  <a href="http://www.nimh.nih.gov/outreach/partners">www.nimh.nih.gov/outreach/partners</a></p>	<p>The NIMH Outreach Partners Program is a nationwide initiative to bridge the gap between research and clinical practice. The program includes national and state organizations in disseminating information about the latest scientific findings about mental disorders and substance abuse; educating the public; and reducing stigma and discrimination. Visit the website for more information and to subscribe</p>

## NOT-FOR-PROFIT INFORMATION

<p>Federal Citizen Information Center  US General Services Administration  1800 F Street, NW  Washington, DC 20405  Phone: 888-878-3256  800-FED-INFO or  800-333-4636  Español available  Website: <a href="http://www.pueblo.gsa.gov">www.pueblo.gsa.gov</a></p>	<p>The Federal Citizen Information Center is a gateway to government information. Questions about all aspects of the federal government can be answered in English and Spanish. The website also links to the following:</p> <ul style="list-style-type: none"> <li>• First Gov.gov for Citizens</li> <li>• Disabilityinfo.gov</li> </ul>
<p>GuideStar  4801 Courthouse Street, Suite 220  Williamsburg, VA 23188  Phone: 757-229-4631  <a href="http://www.guidestar.org/about/">www.guidestar.org/about/</a></p>	<p>GuideStar is a searchable database for non-profit organizations that allows agencies to educate donors about their work. A basic search about an agency can be conducted for free if the non-profit is profiled in the system. The search may include information on an agency's non-profit status and mission for donors to public charities. More in-depth information about an organization can be conducted for a nominal fee.</p>
<p>Internal Revenue Service  Tax Line: 800-829-1040  For Business: 800-829-4933  TDD: 800-829-4059  website: <a href="http://www.irs.gov/charities">www.irs.gov/charities</a></p>	<p>The Internal Revenue Service offers information for the general public and provides a menu for non-profit related information. Visit the website or call one of the telephone numbers listed to the left for other pertinent information regarding tax collection issues.</p>
<p>Office of Minority Health Resource Center  Department of Health and Human Services  P.O. Box 37337  Washington, DC 20013-7337  Phone: 800-444-6472  Website: <a href="http://www.omhrc.gov">www.omhrc.gov</a></p>	<p>The Office of Minority Health advises the Secretary of Health and Human Services on health care issues the effect minorities. The Resource Center provides national resource information on health disparities and referral services on minority issues. Visit the website for additional information and access to the publications.</p>
<p>SCORE  409 Third Street, SW  Sixth Floor  Washington, DC 20024  Phone: 800-634-0245  Website: <a href="http://www.score.org/index.html">www.score.org/index.html</a></p>	<p>SCORE "Counselors to America's Small Business" provides free and confidential small business advice to help you build your business—from idea to start-up to success. Available resource information includes Business Toolbox, Learning Center, and information about alliances that could help you.</p>
<p>Small Business Administration  409 Third Street, SW  Washington, DC 20416  Phone: 800-U-ASK-SBA  Website: <a href="http://www.sba.gov">www.sba.gov</a></p>	<p>The Small Business Administration provides services to America's small businesses through loans, contracts, counseling, and other forms of assistance. The SBA also protects interest of small business and provides assistance for families and businesses to recover for natural disasters. Visit the website and learn how the SBA can possibly assist with your agency needs.</p>

<p>National Mental Health Association Consumer Supporter Technical Assistance Center (NCSTAC) 2001 N. Beauregard Street, 12<sup>th</sup> Floor Alexandria, Virginia 22311 Phone: 800-969-6642 Email: <a href="mailto:ConsumerTA@nmha.org">ConsumerTA@nmha.org</a> Website: <a href="http://www.ncstac.org">www.ncstac.org</a></p>	<p>Materials include: "How to Establish a 501(c)3" "Guide to Proposal Writing" "Fundraising Basics" "Working with the Media" "Working with Volunteers" "How to Develop and Maintain Consumer Advisory Boards"</p>
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## RECOVERY ORIENTED INFORMATION

<p>Boston University Center for Psychiatric Rehabilitation 940 Commonwealth Avenue West Boston, MA 02215 Phone: 617-355-3549 Website: <a href="http://www.bu.edu/cpr">www.bu.edu/cpr</a></p>	<p>The Center for Psychiatric Rehabilitation is a research, training and service organizations that focuses on the improvement of people, programs and service system. You can access information about research, trainings, publications and services on the Center's website.</p>
<p>Copeland Center for Wellness and Recovery P.O. Box 6464 Chandler, AZ 85246 Phone: 866-I DO WRAP or 866-436-9727 or 480-855-3282 Website: <a href="http://www.copelandcenter.com">www.copelandcenter.com</a> or <a href="http://www.mentalhealthrecovery.com">www.mentalhealthrecovery.com</a></p>	<p>The Copeland Center was developed to assist the transformation of lives, programs and mental health systems. The first website for the Copeland Center addresses shifts of mental health care to a prevention and recovery focus. The second website provides a variety of recovery oriented resources including the text on WRAP and other publications.</p>
<p>Institute for Mental Health Research 222 W. Thomas Road, Suite 414 Phoenix, AZ 85013 Phone: 602-406-4360 Website: <a href="http://www.imhr.org">www.imhr.org</a></p>	<p>The Institute for Mental Health Research provides information on research progress of mental health. The website also contains resource links to services and additional information.</p>
<p>National Association of State Mental Health Program Directors (NASMHPD) 66 Canal Center Plaza, Suite 302 Alexandria, VA 22314 Phone: 703-739-9333 Website: <a href="http://www.nasmhpd.org/index.cfm">www.nasmhpd.org/index.cfm</a></p>	<p>NASMHPD represents the state mental health commissioners/directors and their agencies. NASMHPD provides technical assistance and consultation to the Commissioners/Directors on issues regarding special populations and focuses on policy analysis, and consultation to state planning and advisory board as well as consumer and families to ensure that the best practices and current knowledge in mental health are translated into action at the state and local levels.</p>

<p>National Network of Libraries Medicine Phone: 800-338-7657 Website: <a href="http://www.nlm.gov">www.nlm.gov</a></p>	<p>The National Network of Libraries Medicine provides professionals with access to biomedical information and the public to help them to make informed decisions about health. The website features a search portal to health science libraries of medicine and information centers. A list of networks is provided by regions or you can call the 800-number to locate a network near you. The Network also features multilingual health information.</p>
<p>University of Pennsylvania Collaborative on Community Integration 3534 Market Street, 3<sup>rd</sup> Floor Philadelphia, PA 19104 Phone: 215-746-6713 215-746-6713 Website: <a href="http://www.upennrrtc.org">www.upennrrtc.org</a></p>	<p>The UPENN Collaborative includes three partner organizations that provide research, training, technical assistance and information dissemination on community integration. The website offers resource information on a variety of community integration issues including employment, peer support, and transportation.</p>
<p>US Psychiatric Rehabilitation Association 601 North Hammond Ferry Road, Suite A Linthicum, MD 21090 Phone: 410-789-7054 410-789-7682 (TDD) Email: <a href="mailto:info@uspra.org">info@uspra.org</a> Website: <a href="http://www.uspra.org">www.uspra.org</a></p>	<p>The US Psychiatric Rehabilitation Association is an organization of psychiatric rehabilitation agencies, practitioners and organizations and individuals that promote, support and strengthen community-oriented rehabilitation services and resources for people with psychiatric disabilities. The website offers articles, resources, publications and a link for membership. There is also a link to locate local USPRA chapters.</p>

## TECHNICAL ASSISTANCE

<p>ADA Technical Assistance Program Phone: 800-949-4232 Website: <a href="http://www.adata.org">www.adata.org</a></p>	<p>The Technical Assistance Program of materials to increase knowledge about the American with Disabilities Act and accessible information technology. A vast number of infrastructure resources, including publications and videos are available. Ten regional centers are established as one-stop resources on ADA issues. Visit the website for the contact information for your region and for more information about the resources offered by the program. You may also call the toll-free number.</p>
<p>Consumer Organization and Networking Technical Assistance Center (CONTAC) P.O. Box 11000 Charlestown, West Virginia 25339 Phone: 800-825-TECH or 304-345-7312 Email: <a href="mailto:usacontac@contac.org">usacontac@contac.org</a> Website: <a href="http://www.contac.org">www.contac.org</a></p>	<p>CONTAC provides resources to consumers and consumer run programs in the United States. Examples of services include on-site training, curriculum and informational materials; networking and customized activities to promote self-help, recovery, leadership, business management and empowerment as needed. CONTAC is one of the National Technical Assistance Centers on Consumer/Peer-Run Programs.</p>

<p>Info Technology Technical Assistance and Training Center Center for Assistive Technology and Environmental Access 490 10<sup>th</sup> Street NW Atlanta, GA 30318 Phone: 800-948-8262 Email: <a href="mailto:Ittadc@ittadc.org">Ittadc@ittadc.org</a> Website: <a href="http://www.ittadc.org">www.ittadc.org</a></p>	<p>Provides accessible training and technical assistance that leads to understanding regulations of Section 508 of the Rehabilitation Act and Section 255 of the Technology Act to develop, market and make electronic and information technology accessible.</p>
<p>NAMI Support, Technical Assistance and Resource Center (STAR) STAR Center Colonial Place Three 2107 Wilson Boulevard, Suite 300 Arlington, Virginia 22201 Phone: 866-537-STAR 866-537-7827 Email: <a href="mailto:star@nami.org">star@nami.org</a> Website: <a href="http://www.consumerstar.org">www.consumerstar.org</a></p>	<p>The STAR Center provides an array of support, technical assistance and resources to improve and increase the capacity of consumer operated programs to meet the needs of persons living with mental illnesses from diverse communities. The website also provides information en Español. The STAR Center is one of the National Technical Assistance Centers on Consumer/Peer-Run Programs.</p>
<p>National Empowerment Center 599 Canal Street Lawrence, Massachusetts 01840 Phone: 800-power2u or 800-769-3728 978-685-1494 Email: <a href="mailto:info4@power2u.org">info4@power2u.org</a> Website: <a href="http://www.power2u.org">www.power2u.org</a></p>	<p>The National Empowerment Center provides a variety of resource information to support consumer-run organizations. Resources, publications, and a list of programs and services are just a few examples of the resources found on the website. The National Empowerment Center is one of the National Technical Assistance Centers on Consumer/Peer-Run Programs.</p>
<p>National Mental Health Association Consumer Supporter Technical Assistance Center (NCSTAC) 2001 N. Beauregard Street, 12<sup>th</sup> Floor Alexandria, Virginia 22311 Phone: 800-969-6642 Email: <a href="mailto:ConsumerTA@nmha.org">ConsumerTA@nmha.org</a> Website: <a href="http://www.ncstac.org">www.ncstac.org</a></p>	<p>The National Mental Health Association Consumer Supporter Technical Assistance Center provides technical assistance to strengthen consumer organizations. Examples of the forms of TA include research, information materials, and financial aid. The Center also provided a variety of grant opportunities to consumer-run organizations in organizational establishment and mental health transformation. The Consume Supporter Technical Assistance Center is one of the National Technical Assistance Centers on Consumer/Peer-Run Programs.</p>
<p>National Mental Health Consumers' Self-help Clearinghouse 1211 Chestnut Street, Suite Philadelphia, PA 19107 Phone: 800-553-4539 215-751-1810 Email: <a href="mailto:info@mhselfhelp.org">info@mhselfhelp.org</a> Website: <a href="http://www.mhselfhelp.org">www.mhselfhelp.org</a></p>	<p>The Clearinghouse provides resources for mental health consumers on self-help and advocacy as well as peer-run services. Access to publications, training and news resources are available on the web page. Visit the website for a complete list of the services and more. The Clearinghouse is one of the National Technical Assistance Centers on Consumer/Peer-Run Programs.</p>

<p>Peer-to-Peer Resource Center Depression and Bipolar Support Alliance 730 N Franklin Street, Suite 501 Chicago, IL 60610 Phone: 800-826-3632 or 312-642-0049 Website: <a href="http://www.peersupport.org">www.peersupport.org</a></p>	<p>The Peer-to-Peer Resource Center is a national self-help technical assistance center that promotes a model of self-directed recovery for consumers. The Center provides training and certification of peer specialists to foster recovery, independence and community integration. Visit the website for more information of the products provided by the Center.</p>
<p>The Resource Center to Address Discrimination and Stigma (ADS Center) 11420 Rockville Pike Rockville, MD 20852 Phone: 800-540-0320 Bilingual Staff available Email: <a href="mailto:stopstigma@smahsa.hhs.gov">stopstigma@smahsa.hhs.gov</a> Website: <a href="http://www.stopstigma.samhsa.gov">www.stopstigma.samhsa.gov</a></p>	<p>The ADS Center provides technical assistance on developing and preparing anti-stigma initiatives. The website also provides access to Elimination of Barriers Initiative, teleconferences and materials that will useful in anti-stigma campaigns and access to other links.</p>
<p>University of Illinois at Chicago National Research and Training Center on Psychiatric Disability Center on Mental Health Services Research and Policy 1601 West Taylor Street, 4<sup>th</sup> Floor, M/C913 Chicago, IL 60612 Phone: 312-422-8180 312-422-0706 (TDD) Website: <a href="http://www.psych.uic.edu/uicnrtc/">www.psych.uic.edu/uicnrtc/</a></p>	<p>The National Research and Training Center on Psychiatric Disability offers research, training, technical assistance and dissemination activities that promote self-determination for persons with psychiatric disability. The Center addresses five core areas in project activity to promote an increase in self-determination and independence. Visit the website for information on the products, actives, and trainings offered by the Center.</p>

## GENERAL RESOURCES

<p>Department of Education 600 Independence Avenue, SW Washington, DC 20201 Phone: 800-872-5327 or 202-401-2000 Website: <a href="http://www.ed.gov">www.ed.gov</a></p>	<p>The Department of Education supports three departments that address disability and rehabilitative issues for all ages. These programs include National Institute of Disability Rehabilitation and Research, Office of Special Education Programs and Rehabilitation Services Administration. These departments generate, disseminate, and promote new knowledge to improve the options available to disabled persons. Visit the website for the Department of Education for additional information about programs, research outcomes, and publications that may assist in the operations of your organization.</p>
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<p>National Center for the Dissemination of Disability Research Southwest Educational Development Laboratory 211 East Seventh Street, Suite 448 Austin, TX 78701 Phone: 800-266-1832 or 512-476-6861 Website: <a href="http://www.ncddr.org">www.ncddr.org</a></p>	<p>The National Center for the Dissemination of Disability Research provides research, technical assistance and demonstrations activities focus and the dissemination of research funded by NIDRR within the Department of education. Explore the website for information you can review and possibly print on-line.</p>
<p>Partnership for Prescription Assistance Phone: 888-4PPA-NOW or 888-477-2669 Website: <a href="http://www.HelpingPatients.org">www.HelpingPatients.org</a></p>	<p>Provides assistance for individuals who need assistance for prescription medications. An on-line message center is available to contact the agency or call the toll-free number.</p>
<p>The US Department of Health and Human Services 200 Independence Avenue, S.W. Washington, D.C. 20201 Phone: 202-619-0257 Toll Free: 877-696-6775  Website: <a href="http://www.hhs.gov/about/index.html#agencies">http://www.hhs.gov/about/index.html#agencies</a></p>	<p>The link will take you to a list for all the federal agencies and initiatives.</p>



## APPENDIX B

### EXAMPLES OF MISSION STATEMENTS, VALUE STATEMENTS, AND ACTION PRIORITIES OF STATEWIDE CONSUMER ORGANIZATIONS

Following is an appendix of mission statements, value statements, and action priorities of existing and forming statewide consumer organizations. We have included these not only from the Recovery Consortium members but also from some of the other organizations we interviewed.

Our hope is that these examples from existing organizations may help guide your process of deciding on wording and focus as you begin the task of creating your own statewide consumer organization.

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#### *Vermont*

##### **Vermont Psychiatric Survivors, Inc.**

#### MISSION STATEMENT

Vermont Psychiatric Survivors, Inc., is an independent, statewide, survivor-run organization, whose primary purpose is to empower individuals, raise their self-esteem and facilitate mutual peer support among our membership. VPS is open to any and all psychiatric survivors without bias, develops and supports local support groups, and assists individual survivors with individual issues.

In addition: Provides information, referral, and networking services. Fosters leadership and develops employment opportunities. Engages in advocacy to improve mental health services. Provides education about mental illness, recovery and the service system, using outreach to members and organizations.

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## *California*

### **California Network of Mental Health Clients**

#### MISSION STATEMENT

The purpose of the California Network of Mental Health Clients is to support and encourage mental health clients to live at the highest level possible while enjoying full civil and human rights.

#### OBJECTIVES AND PURPOSES

The primary objectives and purposes of this corporation shall be:

- a) To empower clients of the mental health system through self-help groups and networking statewide;
  - b) To confront stigmatizing attitudes about mental health clients in the public, the media, the mental health system, and within mental health clients themselves;
  - c) To provide a strong voice of, by and for mental health clients, to be heard on all issues concerning clients and public policies affecting them in the government, the media and the community;
  - d) To promote and instill the rights of clients in and out of treatment situations, with special attention to the right of freedom of choice;
  - e) To provide every possible reasonable accommodation to enable persons with a psychiatric disability to work and provide a range of employment opportunities from subsidized pre-vocational training and on-the-job skills development to employment comparable to non-disabled individuals in similar positions.
  - f) Other: All other activities and programming relating to mental health client empowerment and our vision or mission.
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## *Ohio*

### **Ohio Advocates for Mental Health**

#### MISSION STATEMENT

The mission of Ohio Advocates for Mental Health is to educate public officials and the community at large about mental health and recovery. Through collaboration and outreach, we offer those in the mental health community the opportunity to belong to a strong leadership and advocacy network which brings about necessary legislative change, assures linkage with needed resources, and promotes the power of self advocacy through peer education.

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## *Maryland*

### **On Our Own of Maryland, Inc.**

#### MISSION STATEMENT

On Our Own of Maryland, Inc., a statewide mental health consumer education and advocacy network, promotes equality in all facets of society for people who receive mental health services and develops alternative, recovery-based mental health initiatives.

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## ***Massachusetts***

### **CHANGE: Consumer/Survivors Helping, Advocating and Networking for Growth and Empowerment**

MISSION STATEMENT: CHANGE is a statewide support and advocacy network of people who have a variety of experiences with the mental health system. Honoring our past we envision an integrated community, which promotes the greatest degree of self-determination. We come together to link resources and engage as equal partners in creating person-centered services.

#### ***We promote the following values:***

##### **RESPECT**

We value RESPECT. It is the foundation for communication. Honoring the dignity and uniqueness of others strengthens our organization and fosters commitment as we take the high ground in accomplishing our mission. We recognize that we must give respect to receive it.

##### **EMPOWERMENT**

We value EMPOWERMENT. We grow and gain confidence as we stand up for ourselves and contribute to our organization by creating a collective, responsible power and commitment toward achieving common goals.

##### **CHOICE**

We value CHOICE. In dignity of being able to take risks, there is freedom and flexibility to consider our options, and learn through consequences of our decisions as we promote wellness and overcome obstacles.

##### **DIVERSITY**

We value DIVERSITY. Welcoming varied viewpoints, beliefs, backgrounds and experiences, we commit to attract and support a membership which is culturally and ethically diverse.

##### **COMMUNITY**

We value COMMUNITY. Demonstrating the power of inclusiveness and support we come together in unity toward a common vision and mission and create a sense of belonging that inspires and nourishes our organizational spirit and energy.

##### **HONESTY**

We value HONESTY. Speaking and hearing truth matters as it establishes our integrity and creates an atmosphere of respect. Clarity and accountability are essential as we work together.

##### **TRUST**

We value TRUST. It is essential for working together and enhances our physical, emotional, and psychological safety as we rely on each other to create a comfortable environment that supports our progressive change.

##### **CREATIVITY**

We value CREATIVITY. Fresh approaches and new ideas can provide changes and solutions to seemingly insurmountable problems and ever-changing circumstances. Group expression releases potential for inspiration and resilience.

## ***Kentucky***

### **Kentucky Consumer Advocate Network (KYCAN)**

*Empowering mental health consumers to have hope, to take personal responsibility, advocate, educate, and to represent the consumer community before public and governmental bodies*

(KYCAN) is a non-profit organization of mental health consumers that promotes the rights, concerns, and issues of persons with mental illnesses in Kentucky. The organization was founded in Nazareth, KY, during 1988, by a small group of concerned mental health consumers. KYCAN encompasses the promotion of self-determination among mental health clients and the avocation of client dignity, community integration without discrimination, and freedom of choice on behalf of mental health clients through public education. KYCAN's efforts are supported by Kentucky's Office of Protection and Advocacy and the Department of Mental Health and Substance Abuse, Community Support Programs, SAMHSA, and other donations.

As consumers of mental health services, we believe in:

#### **Rights...**

- To be equal, to have the ability to better ourselves and to succeed.
- To be informed about our diagnosis/illness and medications/side effects; to participate and make decisions/choices about treatment.
- To receive appropriate, effective services.
- To have food, clothing, and shelter, as well as a job for those who can and wish to work.

#### **Responsibility...**

- To make informed decisions and choices about our lives and not to let others control our lives.
- To set goals, make plans and follow through on our commitments.

#### **Recovery...**

- To help ourselves, realizing that this is the most important part of learning to cope and to live with our illnesses.
- To share our experiences with others, to help our peers succeed, and to educate others about mental illnesses.

#### **Representation...**

- To use ourselves as valuable resources for starting support groups and self-help projects.
- To advocate for changes needed in the system.
- To participate on boards and committees that make decisions about programs and services for persons with mental illnesses.

**Respect...**

- To be regarded by ourselves and others as valuable, talented, and unique human beings.
- To enhance our self-determination and desire to help ourselves, to develop a positive self-image, and to build self-esteem.

**Education...**

- To educate ourselves, our families, peers, and community about mental health issues.
  - To use our knowledge to make intelligent and in-formed decisions about our treatment.
  - To use facts to help eliminate stigma and destroy all "myths about mental illness".
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***Florida***

**Florida Peer Network, Inc.**

**MISSION STATEMENT**

The Florida Peer Network, Inc. is an independent organization of and for persons with psychiatric disabilities. Our mission is to promote recovery, quality of life, advocacy, education, mutual support, peer directed services, and participation in mental health policy design for consumers throughout the state of Florida.

We are a community of persons who know firsthand what does and does not work for recovery. As such, the Florida Peer Network, Inc. serves as the voice of individuals that are directly affected by the policy decisions of the public/private mental health system. We believe this system has much to gain from listening to our combined wisdom and experience, which we offer in good faith. Assisting each other in seeking recovery and maximum quality of life is our central goal.

**ACTION PRIORITIES:**

- Participate in the transformation of the mental health service system towards recovery orientation, consumer direction, holistic and evidence-based practices.
  - Assist DCF in the development of a statewide Office of Consumer Affairs.
  - Implement peer specialist training and certification on a statewide basis.
  - Educate consumers on their legal and civil rights.
  - Grassroots political advocacy on behalf of persons with psychiatric challenges.
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## APPENDIX C

### SAMHSA CONSENSUS STATEMENT ON MENTAL HEALTH RECOVERY

Released February 16, 2006

The Substance Abuse and Mental Health Services Administration today unveiled a consensus statement outlining principles necessary to achieve mental health recovery. The consensus statement was developed through deliberations by over 110 expert panelists representing mental health consumers, families, providers, advocates, researchers, managed care organizations, state and local public officials and others.

“Recovery must be the common, recognized outcome of the services we support,” SAMHSA Administrator Charles Curie said. “This consensus statement on mental health recovery provides essential guidance that helps us move towards operationalizing recovery from a public policy and public financing standpoint. Individuals, families, communities, providers, organizations, and systems can use these principles to build resilience and facilitate recovery.”

The 10 Fundamental Components of Recovery include:

- **Self-Direction:** Consumers lead, control, exercise choice over, and determine their own path of recovery by optimizing autonomy, independence, and control of resources to achieve a self-determined life. By definition, the recovery process must be self-directed by the individual, who defines his or her own life goals and designs a unique path towards those goals.
- **Individualized and Person-Centered:** There are multiple pathways to recovery based on an individual’s unique strengths and resiliencies as well as his or her needs, preferences, experiences (including past trauma), and cultural background in all of its diverse representations. Individuals also identify recovery as being an ongoing journey and an end result as well as an overall paradigm for achieving wellness and optimal mental health.
- **Empowerment:** Consumers have the authority to choose from a range of options and to participate in all decisions—including the allocation of resources—that will affect their lives, and are educated and supported in so doing. They have the ability to join with other consumers to collectively and effectively speak for themselves about their needs, wants, desires, and aspirations. Through empowerment, an individual gains control of his or her own destiny and influences the organizational and societal structures in his or her life.
- **Holistic:** Recovery encompasses an individual’s whole life, including mind, body, spirit, and community. Recovery embraces all aspects of life, including housing, employment, education, mental health and healthcare treatment and services, complementary and naturalistic services (such as recreational services, libraries, museums, etc.), addictions treatment, spirituality, creativity, social networks, community participation, and family supports as determined by the person. Families, providers, organizations, systems, communities, and society play crucial roles in

creating and maintaining meaningful opportunities for consumer access to these supports.

- **Non-Linear:** Recovery is not a step-by step process but one based on continual growth, occasional setbacks, and learning from experience. Recovery begins with an initial stage of awareness in which a person recognizes that positive change is possible. This awareness enables the consumer to move on to fully engage in the work of recovery.

- **Strengths-Based:** Recovery focuses on valuing and building on the multiple capacities, resiliencies, talents, coping abilities, and inherent worth of individuals. By building on these strengths, consumers leave stymied life roles behind and engage in new life roles (e.g., partner, caregiver, friend, student, employee). The process of recovery moves forward through interaction with others in supportive, trust-based relationships.

- **Peer Support:** Mutual support—including the sharing of experiential knowledge and skills and social learning—plays an invaluable role in recovery. Consumers encourage and engage other consumers in recovery and provide each other with a sense of belonging, supportive relationships, valued roles, and community.

- **Respect:** Community, systems, and societal acceptance and appreciation of consumers—including protecting their rights and eliminating discrimination and stigma—are crucial in achieving recovery. Self-acceptance and regaining belief in one's self are particularly vital. Respect ensures the inclusion and full participation of consumers in all aspects of their lives.

- **Responsibility:** Consumers have a personal responsibility for their own self-care and journeys of recovery. Taking steps towards their goals may require great courage. Consumers must strive to understand and give meaning to their experiences and identify coping strategies and healing processes to promote their own wellness.

- **Hope:** Recovery provides the essential and motivating message of a better future—that people can and do overcome the barriers and obstacles that confront them. Hope is internalized; but can be fostered by peers, families, friends, providers, and others. Hope is the catalyst of the recovery process.

The National Consensus Statement on Mental Health Recovery is available at SAMHSA's National Mental Health Information Center at [www.mentalhealth.samhsa.gov](http://www.mentalhealth.samhsa.gov) or 1-800-789-2647.

*SAMHSA is a public health agency within the U.S. Department of Health and Human Services. The agency is responsible for improving the accountability, capacity and effectiveness of the nation's substance abuse prevention, addictions treatment and mental health service delivery systems.*